# Neonatal deaths under Dutch Groningen Protocol very rare despite misinformation contagion

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**Abstract:** The Groningen Protocol specifies criteria for the potential termination of life in severely ill newborns in extremis with untreatable and unrelievable conditions. In September 2006 the Netherlands formally adopted a Regulation incorporating the Protocol. Despite the Regulation's development through extensive professional consultation, endorsement by the Dutch Paediatric Association, empirical data showing a decrease rather than increase in use, and research showing that neonatal euthanasia occurs around the world in the absence of regulation, the Dutch Regulation has sparked controversy. More recently it has been claimed that hundreds of babies a year are killed under its provisions. Forensic analysis reveals the claim to be comprehensively and evidentially false. Wide online dissemination of the claim by mostly religious sources demonstrates confirmation bias and misinformation contagion.

Key words: Netherlands, Groningen Protocol, neonatal euthanasia, palliative sedation, neuromuscular blocker, non-treatment decision, confirmation bias, misinformation contagion, religion

# INTRODUCTION

The Royal Dutch Medical Association (KNMG) estimates that of 175,000 human births in the Netherlands each year, around 650 newborns will die not long after birth, often as a result of severe congenital defects. In the last week of life a dying child experiences a high symptom burden regardless of the underlying disease. Parents and physicians are faced with the dilemma of deciding whether intensive treatment is beneficial or would merely prolong the suffering and dying of the child.

When treatment is not beneficial, there is widespread agreement amongst physicians for withholding or withdrawing treatments and for the alleviation of suffering."<sup>3,4</sup> Analgesics and sedatives are preferred and are regarded as good palliative care even if the interventions may unintentionally hasten death.

These are not merely attitudes, but translate into practice<sup>5</sup> especially in cases of terminal illness, and to a slightly lesser extent when neurological prognosis is particularly poor.<sup>6</sup>

In the mid-1990s, two Dutch court cases of neonatal euthanasia, one of extreme spina bifida and the other of trisomy 13, were determined to have met standards of good medical care. Both neonates had very limited life expectancy and experienced extreme, untreatable suffering. While the verdicts provided some guidance, Dutch paediatricians still clamoured for greater clarity.<sup>7</sup>

Where analgesics and sedatives have been administered, even if they might have (unintentionally) hastened death, the death is medically certified as 'natural': caused by the newborn's underlying illness.

It is sometimes argued that if analgesics and sedatives are continuously administered in proportionate doses, the newborn will not suffer prior to death.<sup>8</sup> However, the KNMG notes that breakthrough, unbearable suffering may still occur, particularly amongst newborns with congenital brain damage or asphyxiation.

Sometimes in these few cases, neuromuscular blockers (NMBs) are administered to relieve gasping. The KNMG states that administration of NMBs usually indicates an intention to hasten death and that hastening death is a last resort. Administration in such circumstances has been described as a humane approach.  $^8$ 

Given that NMBs in this context will hasten death, the death cannot be medically certified as 'natural': it must be reported to the authorities. This gives rise to apprehension amongst physicians and may prompt decisions which may not be in the best interests of the newborn, who may then experience prolonged and intense suffering prior to death.

## THE GRONINGEN PROTOCOL

In the Netherlands in 1995, 43% of neonatal deaths occurred without the need to make medical end-of-life decisions. In the 57% of neonatal deaths preceded by a decision, it was to forgo life-sustaining treatment, 23% with the administration of drugs to alleviate suffering and which might hasten death, and 8% with the administration of drugs whose intention was to hasten death. Practice had changed little by 2001, 5 despite a wide desire of Dutch paediatricians for a formal public control and review process 4 which the Dutch government repeatedly promised but failed to develop.

In 2002, paediatric specialists Eduard Verhagen and Pieter Sauer, Clinical Director and Chairman of Paediatrics respectively at the University Medical Centre Groningen, in close consultation with the Groningen district attorney, developed a draft neonatal euthanasia protocol for the district.

In 2004 there were further calls amongst Dutch paediatricians for a nationwide protocol for neonatal euthanasia in exceptional cases, to be developed with the involvement of the highest level of prosecution in the Netherlands, the Board of Prosecutors General at The Hague. <sup>16</sup>

At law in the Netherlands, the expression 'euthanasia' refers to the deliberate ending of life at the request of the patient. Since a newborn cannot make such a request, it could be argued that the expression 'neonatal euthanasia' is erroneous. However, it is used here merely as a convenient shortening of the expression 'deliberate termination of life of a newborn.'

<sup>†</sup> The exception is when NMBs are already being administered in support of artificial ventilation and are continued upon ventilation withdrawal. This is regarded as palliative care with the intention to prevent severe dyspnoea, pain and discomfort. The KNMG suggests that this is not a reportable death.

The 'Groningen Protocol' was refined and published in 2005, 7 and ratified by the Dutch Paediatric Association (NVK). 17

The five essential criteria of the 2005 Protocol appear in Box 1. In addition to these criteria, the published Protocol also articulates processes for assessment, confirmation, decision making, administration, reporting, and the ongoing support of parents.<sup>7</sup>

**Box 1:** Groningen Protocol: five essential criteria for neonatal euthanasia.<sup>7</sup>

- a. The diagnosis and prognosis must be certain.
- b. Hopeless and unbearable suffering must be present.<sup>[a]</sup>
- c. The diagnosis, prognosis, and unbearable suffering must be confirmed by at least one independent doctor.
- d. Both parents must give informed consent.
- e. The procedure must be performed in accordance with the accepted medical standard.

[a] i.e. not merely anticipated.

Dutch authorities then developed a Regulation which incorporated a version of the Protocol, along with provisions for considering cases of late-term (24+ weeks) abortion. The Regulation came into effect in late 2006.<sup>18</sup>

The KNMG consulted widely about the Regulation and in 2013 published a position paper with recommendations for practice, including suggested revisions to the Regulation. This comprised part of the input to a mandated review of the Regulation conducted by The Netherlands Health Organisation for Research and Development. A revision was approved in December 2015 and Gazetted in January 2016. The portion of the revised Regulation in relation to neonatal euthanasia appears in Box 2.

**Box 2:** Revised 2016 Dutch Regulation for neonatal euthanasia. 19

#### Article 7 [a]

In the event of termination of life of a newborn, the doctor has carefully acted if:

- a. the doctor is convinced there is enduring and unbearable suffering
   of the newborn, which among other things means that the
   discontinuation of medical treatment is justified, that is, prevailing
   medical opinion has established that intervention is futile and
   there is no reasonable doubt about the diagnosis and resulting
   prognosis;
- b. the doctor fully informs the parents of the diagnosis and the resulting prognosis and that both the doctor and parents believe that there is no reasonable alternative solution to the newborn's situation;
- c. the parents have agreed to the termination of life;
- d. the doctor has consulted at least one other independent physician who provides a written judgement on the due diligence of the case, or, if an independent physician cannot reasonably be consulted, the doctor consults with the newborn's healthcare team, who provide a written judgement as to the due diligence of the case;
- e. the termination of life is conducted with due medical care.

The revised Regulation is titled "Regulation of the Minister of Security and Justice and the Minister of Health, Welfare and Sport of December 11, 2015, wherein 885614-145412-PG, establishing a commission for the assessment of reported cases of late abortion and euthanasia in newborns (scheme evaluation late abortion and euthanasia in newborns)." The title is too long for practical use. Therefore, while the Regulation covers considerably more ground than the principles for considering neonatal euthanasia, for the purposes of this discussion and because of the popularity of its use, the expression 'Groningen Protocol' hereafter will refer to the full current Regulation and not merely to the original protocol published by Verhagen and Sauer.

#### THE COMMISSION

To provide deliberative, detailed and authoritative scrutiny of cases reported under its jurisdiction, the Regulation also established the *Central Expert Commission Late Pregnancy Termination and Termination of life in Newborns* (hereafter 'the Commission'). <sup>18</sup> As its name indicates, the Commission reviews not only reported cases of neonatal euthanasia, but also of late term pregnancy terminations in cases of severe, untreatable conditions with limited chance of survival outside the womb.

The Commission's primary role is to advise the public prosecutor as to whether each case notified to it was carried out with due care—as defined in the Regulation—by the attending physician.

The Commission comprises six [five] members: a lawyer, an ethicist and four [three] physicians [number prior to 2016 revision].<sup>19</sup> Each member serves for four [six] years and may be reappointed only once. The Commission's work is supported by a specialist legal secretariat and it publishes regular, detailed reports of its findings.<sup>20</sup>

All notifications are sent not only to the Commission but also directly to the Board of Prosecutors General. The Commission, after investigation, forwards to the prosecution office its determination as to due care of the notified death. If a case is determined to have not met all the due care criteria it must also be reported by the Commission to the State Inspectorate for Public Health.

The prosecution office decides, with the support of the Commission's report but under its own authority, whether prosecution is warranted. The State Inspectorate for Public Health decides, if due care criteria have not been met, what professional medical sanctions are to be applied.

The Regulation does not provide automatic protection for physicians. Each case must be fully assessed and judged as meeting due care criteria, and judged acceptable by the Board of Prosecutors General *and* the Minister of Security and Justice, before the possibility of prosecution can be set aside. However, since the prosecutor's office has agreed that life-ending procedures conducted within the due care criteria of the Regulation shall not result in prosecution, it is unlikely that a physician would be prosecuted where the Commission has judged conduct to be compliant. Case examinations may take six, but not more than twelve weeks, <sup>18</sup> compared with an average of 5.3 months for cases notified to local authorities prior to the establishment of the national Commission. <sup>11</sup>

#### Unrelated to Euthanasia committees

The Commission is separate from and unrelated to the Dutch Regional Euthanasia Review Committees (hereafter 'Euthanasia Committees'), which operate under the Dutch *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001* (hereafter the 'Euthanasia Act'). Each of the five Euthanasia Committees is comprised of at minimum one physician, one ethicist and one lawyer.

A physician who provides voluntary euthanasia or physicianassisted dying under the Euthanasia Act is immune from prosecution. Only cases in which a Euthanasia Committee determines that the requirements were not followed with sufficient care, are referred to the Public Prosecutor.

The Euthanasia Act, and the Regulation developed in part from the Groningen Protocol, are compared in Table 1.

The Euthanasia Act formalises and clarifies in statute the regulatory provisions for rational choice in effect in the 1990s and was developed and enacted in response to overwhelming public desire for such reform. The Groningen Protocol was developed as an entirely separate response to an expressed desire through the 1990s, by Dutch paediatricians for a formal and recognised process for considering hastening death of dying newborns in extremis.

 $<sup>\</sup>ensuremath{^{[a]}}$  Translation from Dutch verified by a native Dutch speaker.

Table 1: Comparison of the Netherlands Euthanasia Act and Regulation/Groningen Protocol

	Euthanasia Act (statutory law)	Regulation/Groningen Protocol
Established	Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001 (came into effect April 2002). [Previously by regulation since 1985.]	Developed 2002; published 2005; endorsed by Dutch Paediatric Association (NVK); formal Regulation adopted nationally Sept 2006; KNMG position paper 2013; formal review 2013; revision adopted Dec 2015, Gazetted Jan 2016
In response to	Public opinion for rational self-choice when faced with intolerable and unrelievable suffering	National call by paediatric specialists for a formal and recognised protocol
Applies to	Mentally competent 12+ year olds (12–16 year olds with parental consent) who are experiencing intolerable and unrelievable suffering, to receive self-administered or physician-administered dying	Termination of life for severely ill and untreatable newborns in extremis; termination of pregnancy after 24 weeks
Reporting body	Dutch Regional Euthanasia Committees	Central Expert Commission Late Pregnancy Termination and Termination of life in Newborns
- URL	https://www.euthanasiecommissie.nl/	http://www.lzalp.nl
- Composition	Five regional Committees: each minimum one physician, one ethicist, one lawyer	One national commission: Four [three, prior to 2016] physicians, one ethicist, one lawyer
Reporting	Mandatory reporting to regional euthanasia commission, collated nationally and annual report of statistics published. If Commission finds a case that fails due care requirements, case reported to public prosecutor	Mandatory parallel reporting to both the Commission and the Board of Prosecutors General (highest level of public prosecutor, at The Hague)
Physician protection	Black-letter law protection for physician who adheres to due care criteria; case reviewed by Committee	No automatic protection. Physician must wait up to 12 weeks for clearance by Commission <i>and</i> prosecutor <i>and</i> Minister
Number of reported cases	From 1,850 in 2003 to 5,306 in 2014	From 2007 to 2014, 16 cases of class 2 late-term abortion; 2 cases of neonatal euthanasia (including one immediately prior to the establishment of the Commission)

#### COMMISSION REPORTS AND EARLIER CASES

Since its establishment in late 2006 the Commission has published detailed reports of cases and findings.<sup>20</sup> For 2007 and 2008 it published annual reports, but from 2009 onwards publication has been biennial due to the low number of reported cases. A summary of cases appears in Table 2.

In the nine years since the Commission was established, sixteen cases of late-term abortion and two cases of neonatal euthanasia have been reported to it,<sup>20</sup> compared with 22 cases of neonatal euthanasia reported to local authorities over nine years prior to the Regulation.<sup>11</sup> Only one case—of late-term abortion—was judged by the Commission to have not met all the due care criteria.

Table 2: Cases reported to the Commission<sup>20</sup>

	Late-term	Neonatal
Year	abortion	euthanasia
2006 [a]	n/a	1
2007	3	0
2008	3	0
2009	1	1
2010	3	0
2011	0	0
2012	2	0
2013	3	0
2014	1	0
Total	16	2

[a] Although 2006 is prior to the official commencement of the Commission's activities, one case of neonatal euthanasia around the time of its establishment is included here for completeness

The two cases of neonatal euthanasia were in regard to Herlitz type epidermolysis bullosa (EB), a fatal and untreatable illness characterised by extreme internal and external blistering.‡

It is estimated that prior to the Regulation, around twenty cases of neonatal euthanasia occurred in the Netherlands each year. <sup>21</sup> The majority of these were in relation to spina bifida, with a small minority of cases in relation to hydrocephalus. In all examined cases it was determined that the newborn would profoundly lack self-sufficiency, with a majority predicted to be unable to communicate and to be permanently dependent on hospitalisation even if survival was anticipated. <sup>11</sup>

Immediately prior to the Regulation's national adoption in late 2006 some 16% of end-of-life decisions in neonatal intensive care units (NICUs) involved the administration of NMBs, either because they were already being administered as part of a maintenance program, or to prevent gasping,<sup>22</sup> the latter mostly as a result of parental request.<sup>23</sup>

Since the Protocol was implemented, the use of NMBs in Dutch end-of-life neonatal cases has decreased<sup>24</sup> and the administration of analgesics and sedatives with no possible life-shortening effects has increased.<sup>25</sup> (Similarly, neonatal end-of-life comfort care practice has increased in North America, especially in cases of severe suffering.<sup>26</sup>) The hypothesised 'slippery slope' has in practice tilted away from rather than towards neonatal euthanasia.<sup>27</sup> Nevertheless, Dutch physician attitudes towards practice and the use of NMBs in neonatal end-of-life management continue to vary widely.<sup>12,25</sup>

# **PRACTICE VERSUS REPORTING**

The Commission has commented in its annual reports on the small number of reported cases.<sup>20</sup> There are a number of explanations for the small number.

Firstly, many Dutch paediatricians believe that it is not the intention of NMB administration to hasten death in a newborn who will die regardless of such administration.<sup>24</sup> Nevertheless, the Commission, in its 2009-2010 report stated clearly that use of

<sup>&</sup>lt;sup>‡</sup> The underlying condition of the 2009 case appears in the 2009-2010 report. The 2006 case was advised by Dr Eric van Wylich of KNMG.

NMBs is reportable under the Regulations.<sup>20</sup> Subsequently, the KNMG clarified that *continuation* of NMBs upon withdrawal of futile artificial ventilation was acceptable and therefore not reportable.<sup>10</sup> Nevertheless, fear of legal consequences has prompted more physicians to administer drugs to relieve pain and suffering and whose effect *might* be to hasten death, rather than consider deliberately hastening death.<sup>24</sup> In practice, the demarcation between comfort care and intentionally hastening death is blurred because the physician's intention can be difficult to establish.<sup>6,28</sup>

Secondly, fewer Dutch physicians now believe that opioids hasten death.<sup>29</sup> Even before the Regulation came into effect there was a decreasing trend in both the secondary goal of hastening neonatal death with opioids (1995, 7.6%; 2001, 5.2%; 2005, 2.3% of all non-sudden deaths) and explicitly intending to end life (1995, 2.4%; 2001, 1.8%; 2005, 0.8%).<sup>30</sup> Thus, a decrease in belief that administration of opioids would hasten death may have translated into a decrease in consequential secondary intention, despite some Dutch physicians continuing to believe that administration of analgesics and sedatives in properly titrated (rather than excessive) doses to relieve suffering reveals an 'intention' to hasten death.<sup>24</sup> In any case, the Dutch public approve of the use of continuous deep sedation at the end of life even if it has a life-shortening effect.<sup>31</sup>

Thirdly, ongoing Dutch healthcare authority initiatives to improve the rate of folic acid supplementation amongst pregnant females, the most recent of which was piloted in 2004, resulted in a 43% reduction in the neural tube defect rate (responsible for spina bifida and anencephaly)<sup>32</sup> compared with a drop of 18% in the USA, 55% in Chile and 78% in Newfoundland where folic acid supplementation of flour is mandatory.<sup>33</sup> The larger decreases occurred in countries with very high pre-supplementation neural tube defect rates. Ontario, whose pre-supplement rate was similar to the Netherland's, experienced a 49% drop after supplementation. Nevertheless, it has been suggested that the Dutch folic acid supplementation program could be further improved, especially amongst women of lower socio-economic status.<sup>34</sup> In addition, improved understanding of how common drugs act as folic acid antagonists in pregnancy may also have contributed.<sup>35</sup>

Fourthly, significant improvements in Dutch neonatal screening—particularly a routine ultrasound check at 20 weeks of gestation—have, in cases of severe foetal abnormality, resulted in greatly increased likelihood of pregnancy termination rather than progression to full term.<sup>27</sup> Of those cases that continue to full term it is likely that the parents will be opposed to intentional hastening of death.

Finally, in longitudinal survey research of Dutch physicians' endof-life decisions for neonates prior to Regulation, a significant proportion of end-of-life decisions consistently included an explicit intention to hasten death (1995, 9%; 2001, 9%; 2005, 8%). This total rate of intentional hastening of death was found to have dropped to 1% in 2010 after the Regulation came into effect.<sup>25</sup>

Therefore, a real and significant decrease in the rate of neonatal euthanasia has most likely occurred through a combination of improved healthcare policies and changes in physician attitudes and behaviours, in addition to a nominal decrease caused by a change in physician beliefs (that opioids don't hasten death).

Regardless of all these changes, withdrawal of life-sustaining interventions remains the main mode of death for severely ill neonates in the Netherlands, followed by deaths in which there is either no opportunity or need to make medical end-of-life decisions.<sup>36,37</sup>

## **N**EONATAL EUTHANASIA IN OTHER COUNTRIES

End-of-life decisions about newborns in extremis with little chance of survival occur widely and not only in the Netherlands.

Across Europe, NICU physicians commonly administer sedatives and analgesics to suppress pain even at the risk of respiratory depression and death (Table 3).<sup>6</sup>

**Table 3:** Multi-national study—the proportion of NICU physicians who have ever taken selected decisions<sup>6</sup>

	Administered sedatives/analgesics	Administered drugs with the purpose
Country	to suppress pain <sup>[a]</sup>	of ending life
Italy	32%	2%
Spain	64%	2%
Sweden	86%	2%
Germany	67%	4%
UK	70%	4%
Netherlands	89%	47%
France	87%	73%

[a] Even at the risk of respiratory depression and death.

The administration of drugs for the purpose of ending life also occurred in every country in the study (Table 3). In France, which has neither an assisted dying law (for competent adults) nor a Groningen-like protocol (for newborns in extremis), the administration of drugs for the purpose of ending life occurred at a very substantially higher rate amongst NICU physicians (73%) than in the Netherlands (47%), which has both protocols.

Clearly, the higher rate in France could not be the result of adopted euthanasia protocols since there weren't any, but rather has been driven by an underlying culture of medical practice.

In the USA, 89% of severely ill neonates received opioids or sedatives—drugs which may have hastened death—on the day of death.<sup>38</sup> Neonatal euthanasia by administration of NMBs was also found to occur in both the USA and Canada,<sup>9,39</sup> despite a prohibitive stance held by the American College of Paediatrics who state that "the taking of innocent life is never a moral act".<sup>40</sup>

The data is unequivocal: euthanasia of neonates in extremis is not an act that is confined to the Netherlands—it "happens everywhere, but when it remains hidden, its abuse does, too."<sup>41</sup> Yet only the Netherlands has a clear and public protocol to guide practice and to provide transparent review of actual cases. It has been argued that other countries could do well to follow the Dutch example.<sup>42</sup>

# **IMPROVING PRACTICE**

There is a desire amongst healthcare professionals around the world to improve the standard and consistency of neonatal end-of-life decision making and care.

For example, Israeli nurse attitudes towards active euthanasia of neonates is similar to their attitudes towards aggressive comfort care (described in the research as 'passive euthanasia'), and they believe that decision making would be improved through more relevant laws and regulations.<sup>43</sup>

In the UK only 2% of NICUs have a written policy on the use of NMBs,<sup>44</sup> although the Royal College of Paediatrics and Child Health have published a framework for practice regarding opioids and sedatives for comfort care.<sup>45</sup>

The French Society of Neonatology has published proposals for improved practice amongst neonatal caregivers, 46 and a 2005 statutory change to end-of-life care rules has resulted in more consultation with parents, better quality conversations, and more humane care of dying newborns. 47 Neonatal euthanasia is still prohibited, however.

Similar initiatives have been pursued in other jurisdictions, though none to date, with the exception of the Netherlands, provides procedures for considering intentional hastening of death in addition to *possible* hastening of death via aggressive comfort care.

#### SCHOLARLY AND MEDICAL CONTROVERSY

The Groningen Protocol has caused controversy in professional medical and lay circles. Publication of the original Protocol in 2005<sup>7</sup> prompted subsequent scholarly criticism, <sup>48-50</sup> although a more recent analysis has concluded that on rare occasions within the defined circumstances, deliberately hastening death may be justifiable.<sup>51</sup>

While some Dutch paediatricians conclude that in some cases the Regulation makes the care they provide less optimal than they would want, in other cases the physician has found positive effects in improved communication with parents, which is beneficial to the parents' grieving process.<sup>24</sup>

The Regulation has been criticised as in conflict with certain principles of bioethics (or 'moral princples'<sup>40</sup>), predisposing behaviour towards a slippery slope, and whose evaluation for enactment in individual cases contains uncertainties.<sup>52</sup> However, these criticisms can be levelled equally at aggressive comfort care, sometimes referred to as 'passive euthanasia,' a practice that is widely accepted. In addition, the empirical evidence not only of reported cases but of underlying Dutch medical practice, run counter to slippery slope hypotheses.

Neonatal euthanasia has been equated to after-birth abortion and therefore open to the same parental choices,  $^{53}$  an argument that has been dismissed as poorly constructed.  $^{54}$ 

Some Jewish scholars argue that while comparing the Regulation with the German Nazi eugenics program is "hysterical," "tactless," "unfair and wrong", it is nevertheless "ethically unacceptable and dangerous" on the basis that it invites a slippery slope of practice evidenced by physician participation in the German program. <sup>55,56</sup> The characterisation has been soundly rejected. <sup>57</sup> The Jewish scholars further argue that neonatal euthanasia necessarily offends the moral principle of non-maleficence, to 'do no harm'. The argument has been challenged, noting that the subjection of a newborn and their parents to inevitable suffering until death occurs itself violates the principle. <sup>58</sup>

Many claims, such as failing to precisely distinguish between cases of certain death and survival or to precisely measure suffering; permitting parents to commit infanticide to avoid burdensome care; letting physicians decide quality of life acceptability and the morality of their own actions; failing to prevent spina bifida; and other reasons, "rest on a serious misunderstanding, and, together, they give a highly distorted picture of the Protocol." This analysis has drawn a lively exchange of perspectives, both positive <sup>59,60</sup> and negative. <sup>61,62</sup>

#### MISINFORMATION CONTAGION

Misinformation about the Regulation is common amongst nonmedical commentators who are in principle opposed to intentional hastening of death.

On 12<sup>th</sup> June 2013 the KNMG issued a media release announcing that it had published a position paper on 'Medical end-of-life decisions in neonates with very serious defects'.¹ The media release stated that of around 175,000 babies born each year in the Netherlands, "around 650 infants will die, usually as a result of very severe congenital defects and in spite of the best possible intensive care treatment." The position paper to which the media release refers, provides guidance to Dutch medical practitioners, commending interventions to try and save life, use of palliative (comfort) care when interventions become futile, ending of life only if the newborn is still in extremis even with optimal comfort care, and suggests how the physician might consult to reach shared decisions.¹0

The KNMG was absolutely clear: 650 babies a year were likely to *die*. Some newborns die from catastrophic malformities shortly after birth, some die despite attempted medical interventions and some die after withdrawal of futile interventions and administration of comfort care, possibly aggressive. Death as a result of an intervention whose direct intention is to hasten death, is rare.

Despite this clarity, just two days after the KNMG media release, a range of commentators—many with direct links to conservative (Christian) faiths—falsely claimed that the KNMG had said that some 650 babies a year *could* be or *would* be eligible to be *euthanized* (Table 4).

In a particularly unfactual report, Paul Russell<sup>63</sup> claimed that the Regulation had been 'relaxed' and that it "was said to be responsible for the deaths of about 25 newborns with spina bifida each year." Russell provided no source for his claims. In fact, before the Regulation came into effect, around 20 neonatal euthanasia cases occurred each year, mostly in relation to spina bifida.<sup>21</sup> Since the Groningen Protocol was first published, the provisions have been tightened rather than relaxed, and since coming into national force in late 2006 there have been just two reported cases of neonatal euthanasia (Table 2), neither of which involved spina bifida.

After a hiatus of negative articles in 2014, the erroneous claims recommenced in earnest from the start of 2015 and became more strident, including claims that 650 babies a year *were* or *are euthanized* (Table 4), a charge led by Sarah Zagorski, 64 Sue Reid 55 and Thaddeus Baklinski. 66 Many commentators promoted these articles or penned their own derivatives.

Table 4: A chronological history of false '650 babies euthanized' claims following the KNMG's media release of 12 Jun 2013 [a]

Date	Author	Publication	Article title	Claim/link
14 Jun 2013	Michael Cook; Catholic reporter	BioEdge; conservative religious blog <sup>67</sup>	"Put disabled babies out of our misery, say Dutch doctors"	"the KNMG suggests that about 650 might be cases which would be worthy of euthanasia"
14 Jun 2013	Michael Cook; Catholic reporter	Mercatornet; religiously- inspired blog <sup>68</sup>	"Please, doctor, put him out of our misery"	"the KNMG suggests that about 650 might be cases which would be worthy of euthanasia"
14 Jun 2013	Alissa Robertson	World; conservative Christian magazine <sup>69</sup>	"Euthanazing sick babies to spare parents' suffering"	"The KNMG touted that out of the 175,000 babies born in the Netherlands each year, 650 might have disabilities necessary for euthanasia"; cites Cook's Mercatornet article
14 Jun 2013	Paul Adams	Ethics, Culture and Policy; conservative religious blog <sup>70</sup>	"The Dutch solution to parents' suffering: Kill their newborns"	Reproduces and links to Cook's BioEdge article
17 Jun 2013	Peter Saunders; CEO of UK Christian Medical Fellowship	Christian Medical Comment; own blog site <sup>71</sup>	"Belgium and the Netherlands escalate their children's euthanasia programmes"	Repeats Cook/BioEdge claim (above)
17 Jun 2013	S. Brinkmann	Women of Grace; Catholic apostolate <sup>72</sup>	"Children in crosshairs of euthanasia"	"Of the 175,000 babies born every year in The Netherlands, the KNMG suggests that about 650 might be cases which would be worthy of euthanasia"; cites Cook's Mercatornet article

Date	Author	Publication	Article title	Claim/link
18 Jun 2013	Peter Saunders; CEO of UK Christian Medical Fellowship	LifeSiteNews; promoting "traditional Judeo-Christian principles" <sup>73</sup>	"Bitter irony: children once again to be euthanized in Belgium/Netherlands 70 years after Nazis" (with SS officer photo)	Reproduces own article from Christian Medical Comment
19 Jun 2013	Alex Schadenberg	Euthanasia Prevention Coalition, lobby group blog <sup>74</sup>	"Belgium and the Netherlands escalate their child euthanasia programmes"	Reproduces and links to Saunders' Christian Medical Comment article
19 Jun 2013	Paul Russell; Australian Family Association	HOPE; Australian anti- euthanasia blog <sup>75</sup>	"Belgium and the Netherlands escalate their children's euthanasia programmes"	Reproduces and links to Saunders' Christian Medical Comment article
19 Jun 2013	Editorial	Care Not Killing; UK faith-backed anti-euthanasia lobby group <sup>76</sup>	"Escalation of child euthanasia"	Republishes Saunders' LifeSiteNews article
Later 2013	Editorial	Patients Rights Council; USA anti-euthanasia lobby group <sup>77</sup>	"Dutch doctors propose killing disabled babies so parents don't suffer"	Précis of Cook/BioEdge claim, "KNMG estimates possibly 650 would be eligible for euthanasia"
24 Sep 2013	Paul Russell; Australian Family Association	HOPE; Australian anti- euthanasia blog <sup>63</sup>	"Euthanasia requests in The Netherlands more than double in six years"	"the relaxation of the Groningen protocol" "The Dutch Medical Association estimated that there might be up to 650 cases a year for this extended child-euthanasia"
7 Apr 2014	Denise Cooper-Clarke; convenor Bioethics task group	Ethos; centre for Christianity and society <sup>78</sup>	"Child euthanasia in Belgium: The relentless logic of 'dying with dignity"	"The Royal Dutch Medical Association (KNMG) has said that of the 175,000 babies born every year in the Netherlands, about 650 might be cases which would warrant euthanasia"
2 Jan 2015	Sarah Zagorski, DPP at Christian-based Colorado Family Action	LifeNews; pro-life publication <sup>64</sup> (also promoted on linkis.com <sup>79</sup> )	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	"In 2013, 650 babies died under Holland's assisted suicide law because their parents deemed their suffering too difficult to bear"
2 Jan 2015	Sue Reid	Daily Mail Australia <sup>65</sup>	"The country where death is now just a lifestyle choice"	"The Royal Dutch Medical Association estimates that 650 newborns are killed every year"
2 Jan 2015	Donna Edmonds; self- declared 'Christian mother'	Breitbart News; founded by conservative right USA publisher, Andrew Breitbart <sup>80</sup>	"650 babies euthanized in the Netherlands under right to die law"	"According to the Royal Dutch Medical Association, as many as 650 babies are killed each year"
2 Jan 2015	Editorial	Nuzzel	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	Summary of and link to Zagorski's LifeNews article
3 Jan 2015	Steven Ertelt; pro-life blogger	Google+ 81	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	Introduces and links to Zagorski's LifeNews article
3 Jan 2015	'alexc'	Tinnitus News <sup>82</sup>	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	Introduces and links to Zagorski's LifeNews article
3 Jan 2015	Editorial	Lumiere Charity; Christian blog <sup>83</sup>	"Candle has been lit in remembrance of babies euthanized in Netherlands"	Links to both Zagorski's LifeNews and Edmunds' Breitbart articles; "Lumiere Charity has received report that 650 babies were euthanized in 2013 under the assisted suicide law may these innocent little ones rest in peace"
3 Jan 2015	Adrian Hilton	'Archbishop Cranmer' blog <sup>84</sup>	"Lord Carey is wrong to support state- sanctioned assisted suicide"	"or the Netherlands, where 650 babies were 'put to sleep' in 2013, many because their parents were unable to bear their children's suffering"
3 Jan 2015	Editorial	Bible Prophecy Tracker <sup>85</sup>	"650 babies euthanized in the Netherlands each year under right to die law"	Extract of and link to Edmonds' Breitbart article
4 Jan 2015	Editorial	Youth Defence; pro-life lobby group (Facebook) <sup>86</sup>	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	Introduces and links to Zagorski's LifeNews article; "In 2013, 650 babies died under Holland's assisted suicide law because their parents or doctors deemed their suffering too difficult to bear"
5 Jan 2015	Editorial	RomansTwelveTwo.com; conservative Christian blog <sup>87</sup>	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	Reproduces Zagorski's LifeNews article
5 Jan 2015	Thaddeus Baklinski; Catholic writer	LifeSiteNews; promoting "traditional Judeo-Christian principles" 66	"Up to 650 babies euthanized every year in Holland: report"	"As many as 650 babies are euthanized every year in the Netherlands reports the Royal Dutch Medical Association (KNMG)"
6 Jan 2015	Editorial	Free Republic; conservative blog site <sup>88</sup>	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	Reproduces and links to Zagorski's LifeNews article
5 Jan 2015	'Tim'	The Black Kettle; conservative evangelical Christian blog <sup>89</sup>	"Up to 650 babies euthanized (murdered) every year in Holland: report"	"As many as 650 babies are euthanized every year in the Netherlands because they are believed to be suffering or because a newborn's imminent natural death is emotionally distressing for the parents, reports the Royal Dutch Medical Association (KNMG)." Cites Baklinski's LifeSiteNews article
6 Jan 2015	Susie Allen	Jill Stanek; pro-life blog <sup>90</sup>	"Pro-life blog buzz 1-6-15"	"ProLifeBlogs links to The Black Kettle's post that says 650 babies are euthanized yearly in the Netherlands"; Black Kettle in turn cites Baklinski's LifeSiteNews article
7 Jan 2015	Admin	lona Institute for Religion and Society <sup>91</sup>	"Netherlands euthanises 650 babies annually"	"Some 650 newborn infants are euthanised in The Netherlands every year, it has emerged"

Date	Author	Publication	Article title	Claim/link
Early 2015	Editorial	Rochester Area [New York] Right To Life Committee <sup>92</sup>	"Holland's slippery slope: 650 babies a year"	"One of the more horrifying aspects is that each year as many as 650 babies are euthanized"
9 Jan 2015	'DCG'	Fellowship of the Minds; conservative religious blog <sup>93</sup>	"Up to 650 babies euthanized every year in Holland"	Reproduces Baklinski's LifeSiteNews article
9 Jan 2015	Tom Wilson	'First Things' blog; Institute of Religion and Public Life <sup>94</sup>	"Europe's euthanasia craze"	"The Royal Dutch Medical Association estimates that 650 such newborns are terminated each year [because it is distressing for parents to watch them suffering]"
9 Jan 2015	John Tertullian & Contra Celsum	Theology Geek NZ <sup>95</sup>	"Those who hate God, end up loving death"	Quotes and links to Edmunds' Breitbart article
9 Jan 2015	Editorial	WIFM Radio; evangelical Christian broadcaster <sup>96</sup>	"Articles for 01/09 Signs Of The Times"	Reproduces Edmunds' Breitbart article
10 Jan 2015	Editorial	Christian Telegraph <sup>97</sup>	"Up to 650 babies euthanized every year in Holland: report"	Summarises and links to Baklinski's LifeSiteNews article
11 Jan 2015	Editorial	SermonAudio.com <sup>98</sup>	"Up to 650 babies euthanized every year in Holland: report"	Summarises and links to Christian Telegraph article, which summarises and links to Baklinski's LifeSiteNews article
12 Jan 2015	Editorial	Anglican Network in Canada <sup>99</sup>	"Euthanasia"	"After a decade of legalized assisted dying in the Netherlands, it is estimated that as many as 1 in 3 deaths in the country are from euthanasia – including 650 babies each year", links to Edmonds' Breitbart article
Jan 2015	Editorial	Crossmap.com; conservative Christian portal <sup>100</sup>	"Up to 650 babies euthanized every year in Holland; report"	Summarises and links to Baklinski LifeSiteNews article; also links to Christian Telegraph article which itself links to Baklinski's LifeSiteNews article
Jan 2015	Editorial	Catholic Messages USA <sup>101</sup>	"Catholic Reports Two"	"In 2013, 650 babies died under Holland's assisted suicide law because their parents or doctors deemed their suffering too difficult to bear"; links to Zagorski's LifeNews article
Jan 2015	'PoniranSt.Therese'	Micronesia Forum <sup>102</sup>	"Doctors euthanize 650 babies"	Links to Zagorski's LifeNews article
Jan 2015	'Director'	4MyCanada.ca; conservative Christian youth lobby group <sup>103</sup>	"Doctors euthanize 650 babies under assisted dying law in the Netherlands"	Links to Zagorski's LifeNews article
1 Feb 2015	Editorial	Anglicans for Life <sup>104</sup>	"End of life bibliography"	Summarises and links to Cook's 2013 BioEdge article
7 Feb 2015	Admin	True Dignity Vermont; anti- euthanasia lobby group <sup>105</sup>	"Up to 650 babies euthanized every year in Holland: report"	Links to Baklinski's LifeSiteNews article.
16 Feb 2015	Editorial	Quartermaster of the Baroque; orthodox Catholic blog <sup>106</sup>	"These are troubling times!"	"In the Netherlands, where euthanasia has gained acceptance, as many as 1 in 33 people have died this way over the past decade, including 650 babies who are being killed each year, 'so that their parents don't have to witness them struggle with disability or disease.""
22 Feb 2015	Shafer Parker; turning to God's word	Hawkwood Baptist Church <sup>107</sup>	"How should Christians think about assisted suicide and euthanasia: Genesis 9:5–6"	"In 2013, 650 babies died under Holland's assisted suicide law because their parents or doctors deemed their suffering too difficult to bear."
24 Feb 2015	'Katie'; Lutheran pro- lifer	Pro Life Pro Liberty <sup>108</sup>	"Human rights for all humans"	" 650 babies a year, euthanized so that their parents don't have to witness them struggle with disability or disease"; links to Edmonds' Breitbart article
Feb 2015	Editorial	Shelby County Right To Life <sup>109</sup>	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	Shortened version of Zagorski's LifeNews article
Feb 2015	Editorial	Campaign Life Coalition <sup>110</sup>	"Ask your MP to uphold our laws against euthanasia" [suggested letter to MPs]	"Today there are more than 650 annual cases of euthanasia WITHOUT REQUEST OR CONSENT in the Netherlands. They euthanize children, including newborns with birth defects."
Feb 2015	Editorial	Terri Schiavo Life&Hope Network <sup>111</sup>	"Holland: up to 650 babies euthanized every year"	"As many as 650 babies are euthanized every year in the Netherlands because they are believed to be suffering or because a newborn's imminent natural death is emotionally distressing for the parents, reports the Royal Dutch Medical Association (KNMG)"; cites LifeSiteNews
4 Mar 2015	Ryan Anderson; DeVos Center for Religion and Civil Society	Heritage Foundation; conservative think tank for 'traditional American values', DeVos Center is a division <sup>112</sup>	"Always care, never kill: How physician- assisted suicide endangers the weak, corrupts medicine, compromises the family, and violates human dignity and equality"	"A 2013 Netherlands commission on euthanasia argued that as many as 650 infants per year should be eligible for euthanasia"
29 Mar 2015	Helena Glass; evangelical writer	Helena Glass.net 113	"The Netherlands - a sheep without a shepherd"	"In the Netherlands it is estimated that more than 650 babies are euthanized every year because the parents don't want to raise a child that has some handicap"
7 Apr 2015	'Pin Ar'	Blogspot <sup>114</sup>	"What is physician-assisted suicide and is it practiced morally in the Netherlands?"	"'according to the Royal Dutch Medical Association, as many as 650 babies are killed by doctors each year' under the

Date	Author	Publication	Article title	Claim/link
				verdict of 'the Groningen Protocol'"; cites Zagorski's LifeNews article
14 Apr 2015	Ryan Anderson; DeVos Center for Religion and Civil Society	Heritage Foundation; conservative think tank for 'traditional American values', DeVos Center is a division <sup>115</sup>	"Global experience shows that physician- assisted suicide threatens the weak and vulnerable"	"A 2013 Netherlands commission on euthanasia argued that as many as 650 infants per year should be eligible for euthanasia"
1 May 2015	Jennifer Rast	Rightwingerz.com; conservative Christian portal <sup>116</sup>	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	Extract of and links to Zagorski's LifeNews article
2 Aug 2015	Patrick Flanagan; Irish Catholic writer	European Guardian; 'New Right' blog <sup>117</sup>	"The physically healthy are euthanised in BeNeLux"	"650 babies are killed each year in the Netherlands"; links to Edmunds' Breitbart article
15 Aug 2015	Alex Muñoz	Prezi presentation <sup>118</sup>	"Euthanasia"	"According to the Royal Dutch Medical Association, '650 babies died in 2013 under 26691"; 26691 is the Euthanasia Act, which doesn't apply to anyone under 12 years old
25 Aug 2015	Submission to Parliament of Victoria, Australia	FamilyVoice Australia; a Christian voice for family, faith and freedom <sup>119</sup>	"Submission [878] for the inquiry into end of life choices to the Legal and Social Issues Committee"	"The Royal Dutch Medical Association has estimated that of newborn babies alone, some 650 are killed every year"; cites Reid's Daily Mail article
Aug 2015	Richard Ritenbaugh	Church of the Great God <sup>120</sup>	"Euthanizing a civilization"	"The Netherlands estimates that 650 newborns are euthanized each year simply because their parents are distressed by the fact that these babies are weak or sickly"
3 Sep 2015	Elaine Marlowe Mitchell	Murder in a Hospital; Christian pro-life blog <sup>121</sup>	"Killed the baby save the panda: Chronic disease, disability, mental illness or existential despair"	"In 2013, 650 babies killed in Holland because they were deemed unfit for life"; "in Holland where euthanasia is legal, it has also become legal to kill a baby if the parents or the hospital feel that the child would not have a good quality of life"
10 Sep 2015	Rick Jensen; conservative talk show host on WDEL	Cagle Cartoons <sup>122</sup>	"In California, a right to die"	"The Royal Dutch Medical Association estimates that 650 newborns are killed every year because they fall into this category"; cites Reid's Daily Mail article
10 Oct 2015	Editorial	Illinois Family Institute; conservative Christian lobby group <sup>123</sup>	"Global experience shows that physician- assisted suicide threatens the weak and marginalized"	Reproduces Anderson's Heritage Foundation article of the same title
13 Oct 2015	Rick Jensen; conservative talk show host on WDEL	Fort Madison Daily Democrat <sup>122</sup>	"In California, a right to die"	"Imagine 650 babies (not fetuses, babies) put to death because living with disabilities would make their lives difficult. It's real, not imagination. The Netherlands has"
26 Oct 2015	Larry Peterson	Catholic365.com <sup>124</sup>	"Euthanasia: The catastrophe of honouring 'non-life"	"Of course, in the Netherlands, doctors euthanized 650 babies in 2013. I mean babies and even toddlers who were alive"
Nov 2015	Editorial	Californian Nurses for Ethical Standards; pro-life nursing group <sup>125</sup>	"Where have all the babies gone? 650 babies euthanized"	"Just over 10 years ago, assisted dying was legalized in the Netherlands It's now reported that about 650 babies have been euthanized each year so that their parents wouldn't have to see them struggle with disability or disease"; cites Edmonds' Breitbart article
21 Jan 2016	'Chrystal-J'	Christian Forums <sup>126</sup>	"Doctors euthanize 650 babies under assisted suicide law in the Netherlands"	Summary of and links to Zagorski's LifeNews article
7 Mar 2016	Tribune News Service	Personal Liberty; founded by 'ultra-conservative' USA author Bob Livingston <sup>127</sup>	"Allowing doctors to kill undermines solidarity and corrupts medicine"	"Euthanasia also can lead to infanticide. A Netherlands commission argued in 2013 that as many as 650 infants per year should be eligible for euthanasia on the basis of the children's 'poor prognosis and very poor expected quality of life"

[a] Includes main article content only: excludes reader comments which make these claims. Not an exhaustive list.

Zagorski and Reid in particular not only misunderstood which regulation applied to neonatal euthanasia—it's the 'Groningen Protocol' Regulation, not the Euthanasia Act—but in wrongly blaming "assisted suicide law" for perceived wrongs, failed to explain how a newborn would have the capacity to form an intention to suicide or to implement the decision.

The extensive online repetition of false claims demonstrates powerful confirmation bias: the tendency to select, consume and remember attitude-affirming information and to avoid and forget contradictory information. <sup>128,129</sup>

Recent research suggests that religious individuals who are opposed to a particular issue are more susceptible to confirmation bias than are those who support the issue, in both the selection and consumption of attitude-confirming information.<sup>130</sup>

The widespread dissemination of erroneous information about neonatal euthanasia is 'misinformation contagion' in the

epidemiological sense that one commentator 'infects' others via digitally-mediated transmission, with confirmation bias serving as an amplifying catalyst.

On Australian national TV panel conversation program 'QandA' on 9 November 2015, audience member Luke Formosa stated that: "Findings from the Netherlands Euthanasia Report in 2014 indicate...550 newborn babies with diseases or disabilities were killed." 131 Panel member Andrew Denton immediately disputed the claim, and published an evidence-based refutation. 132

The exchange stimulated controversy and Formosa was afforded the opportunity to provide a full reply. His reply did not address the issue of 550 (or 650) babies being euthanized in the Netherlands and neither did any of the citations he provided.

Australia's 'The Conversation' engaged independent scholar Professor Colleen Cartwright to examine the claim. Cartwright found "no credible evidence to support the claim that 550 babies were

*killed last year under Dutch euthanasia laws*," an assessment endorsed by Associate Professor Lorana Bartels and senior Dutch paediatrician Dr Jan F. Koper.<sup>134</sup>

# **CONCLUSION**

This paper confirms and extends Cartwright's conclusions that there is 'no credible evidence' for hundreds of neonatal euthanasia cases every year in the Netherlands. Indeed, this paper identifies the source of the claimed 650 babies figure, explains how it has been profoundly and widely misrepresented, reports the relevant policies, regulations and empirical research data showing improvement rather than deterioration of medical practice, and identifies many of those who have participated in this misinformation contagion.

The claims not only have 'no credible evidence,' but a forensic analysis reveals them to be comprehensively and evidentially false.

In summary, misinformation contagion—underpinned by confirmation bias—has occurred amongst opponents of the Groningen Protocol/Regulation, wrongly claiming that hundreds of newborns may be or actually are 'euthanized,' 'killed' or 'murdered' each year under its provisions, and in the face of evidence to the contrary:

- Neonatal euthanasia occurs in countries across the world regardless of laws prohibiting such acts, and is therefore not caused by such regulation.
- The Regulation was developed and refined over years of extensive professional consultation, including the Dutch Paediatric Association, the KNMG and the Board of Prosecutors General at The Hague, in response to ongoing demand by Dutch paediatricians. It permits, only as a last resort, the active hastening of death of a newborn in extremis when even the best palliative care can't help.
- The Regulation has restricted (not relaxed) the circumstances in which a newborn's death may be hastened—severe suffering must be present and not merely anticipated; there must be no reasonable alternative solution—and adds onerous reporting and investigation steps.
- Physicians do not receive black-letter legal protection for their
  actions (as they do under the Euthanasia Act for adults), and
  must subject each and every case to detailed medical and legal
  scrutiny across three levels: the investigating Commission, the
  Board of Prosecutors General at The Hague, and the Minister
  for Security and Justice.
- The rate of reported neonatal euthanasia in the Netherlands has decreased (not increased) under the Regulation: a total of two cases between 2006 and 2014 compared with 22 cases reported to local authorities between 1997 and 2004.
- There has been a decrease (not increase) in both the use of NMBs and in the total rate of intention to hasten the death of neonates in extremis in the Netherlands since the Regulation came into effect. Communication with parents has improved.
- Dutch physicians report fear of prosecution as a reason for decreased consideration of neonatal euthanasia.
- Other changes such as improvements in antenatal screening and folate supplementation provide additional compelling explanations for the decrease in Dutch neonatal euthanasia.

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