

PRENATAL GENETIC TESTING PROTOCOL FOR CATHOLIC HEALTHCARE

INTRODUCTION

Prenatal Genetic Testing (PGT) refers to tests that may be performed during pregnancy to either screen for or diagnose a birth defect or genetic condition in an unborn child. Such testing can also determine the child's sex. When performed for a morally licit reason, PGT can assist healthcare workers in managing the pregnancy and in providing the best care possible to both mother and unborn child. However, research shows that many people opt for PGT with the intent to abort if the results indicate the baby may have a genetic condition such as Down syndrome, or even if the sex is not the one desired.¹

While Catholic healthcare does not and may not perform abortions, there is serious concern that Catholic organizations and their employees could be complicit in abortions that follow PGT, especially if there is clear prior intent to abort if the test result is not favorable. Such proximity to the immoral and intrinsically evil act of abortion would constitute illicit cooperation with evil. As *Donum Vitae* instructs, "[prenatal testing] is gravely opposed to the moral law when it is done with the thought of possibly inducing an abortion depending upon the results".² This teaching is reflected in the Ethical and Religious Directives, no. 50.³

In recent years, PGT has become a routine part of prenatal care. The rationale for such testing is to provide the mother with the opportunity to either prepare for the birth of an affected child or to abort her child. Studies show that the vast majority of babies found prenatally to have Down syndrome are aborted.⁴ Thus, potential complicity with the evil of abortion is neither remote nor rare.

Although PGT is not evil in itself, it can be used for evil purposes under certain circumstances, that is, if a patient intends to abort if test results are not desirable. The moral neutrality of PGT has also been compromised by what the medical community readily acknowledges is the real possibility that information from PGT will lead women to face the decision of whether to continue or terminate their pregnancy.⁵ As Father Tad Pacholczyk of the National Catholic Bioethics Center points out, "[PGT] does

¹ See: James Linn, "Testing for Down syndrome in Catholic Health Care: Complicity in Eugenic Abortion" (2019), *The Linacre Quarterly*. Carolyn Laabs, "Prenatal Genetic Screening and Potential Complicity in Abortion: Considerations for Catholic Health Care" (2020), *The Linacre Quarterly*. Amy Harmon, "Genetic Testing + Abortion = ???" *The New York Times* (May 13, 2007) <https://www.nytimes.com/2007/05/13/weekinreview/13harm.html? r=1&oref=slogin>. Elizabeth Ring-Cassidy and Ian Gentles, "The Impact of Abortion after Prenatal Testing," *Women's Health after Abortion*, <https://afterabortion.org/the-impact-of-abortion-after-prenatal-testing/>.

² Congregation for the Doctrine of the Faith. 1987. *Donum Vitae, Instructions on Respect for Human Life in Its Origin and on the Dignity of Procreation Replies to Certain Questions of the Day: I. Respect for Human Embryos* (February 22): 2. https://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19870222_respect-for-human-life_en.html

³ United States Conference of Catholic Bishops. 2018. *The Ethics and Religious Directives of Catholic Health Care Services*, 6th ed. <http://www.usccb.org/about/doctrine/ethical-and-religious-directives/upload/ethical-religious-directives-catholic-health-service-sixth-edition-2016-06.pdf>

⁴ See Linn, Laabs, Harmon, Ring-Cassidy and Gentles.

⁵ Josephine Johnston, Ruth M. Farrell, and Erik Parens, "Supporting Women's Autonomy in Prenatal Testing," *The New England Journal of Medicine* (2017, August 10, 377:6,505-507. Adrienne Asch, PhD and David Wasserman, JD, "Informed Consent and Prenatal Testing: The Kennedy-Brownback Act," *AMA Journal of Ethics*, in: *Virtual Mentor*. 2009; 11(9):721-724. doi: 10.1001/virtualmentor.2009.11.9.oped1-0909.

have its valid uses and applications, but the temptation to misuse it is a serious one, so the decision to carry out such testing must be made very carefully and within a limited set of circumstances."⁶

PGT is an optional screening which is generally offered to pregnant women for Down syndrome or other genetic anomalies (First Trimester Screening), or to couples or individuals who are identified as being at risk for passing on a particular genetic condition. PGT could also be requested by the pregnant woman. In Catholic healthcare, PGT should only serve its morally good purpose, that is, to help parents and providers prepare for the birth of a child.

The primary goals of this protocol is to guide the Catholic healthcare organization and provider in (1) helping individuals make ethically sound healthcare choices for their unborn children, and (2) avoiding immoral cooperation with the evil of abortion.

1. PROVIDING PGT: A PRE-TEST COUNSELING

According to Jay Bringman⁷, women who undergo PGT and receive an abnormal (or non-desired) result have three options: (1) continue with the pregnancy and deliver the baby; (2) have the pregnancy terminated; and (3) continue with the pregnancy and give the baby for adoption. In general, Bringman explains, there are three scenarios that a Catholic provider may face while counseling for PGT:

- a) The patient who states prior to the testing that under no circumstances would she consider pregnancy termination for a test with undesired results.
- b) The patient who unequivocally states that she would have a pregnancy termination if the results are undesired. She may or may not already have plans in place for a termination.
- c) The patient who is uncertain as to what she would do with the results if they are undesired. She may or may not terminate the pregnancy and is unable to make this decision until the results are available to her. This, according to Bringman, is the most common scenario.

Obviously, the first scenario does not present any moral challenge for the Catholic provider; however, Catholic healthcare organizations should deny PGT to patients who fall into scenario (b); failing to do so would constitute an immoral cooperation with evil.

Scenario (c) presents a significant challenge: "the patient who is uncertain as to what she would do with the results if they are undesired." In this case, the Catholic provider should engage the patient in order to achieve moral certitude about her intention in taking the test.

2. PROTOCOL FOR PGT

PGT will be performed by the provider **only after the following pre-test counseling takes place:**

- a) The provider explains that the test is optional.
- b) The provider explains the scope and goal of the test, which is to collect genetic information about the unborn child to assist parents and healthcare workers in the proper care of the child.
- c) The provider explains that Catholic healthcare organizations do not perform abortions, and would not consent to any decision to directly terminate the pregnancy.

⁶ Rev. Tad Pacholczyk, (2006, August), "Temptations in Prenatal Testing," *Making Sense of Bioethics*, https://www.fathertad.com/files/1514/7025/5350/MSOB_014_Temptations_in_Prenatal_Testing.pdf

⁷ Jay J. Bringman, "Invasive prenatal genetic testing: A Catholic healthcare provider's perspective", *The Linacre Quarterly* (2014).

- d) The provider explains the resources available to assist the couple or individual pregnant woman in case the results of the test show that the child may have Down syndrome or other genetic condition (see # 2 “Parents of a child with Down Syndrome or other Genetic Conditions”).
- e) The provider offers detailed information of the procedure according to the policies of the organization, and obtains informed consent.
- f) The provider obtains the patient’s intention by completing the attached “Expression of Intent Regarding Prenatal Genetic Testing” form.
- g) In the case of a patient or legal guardian with an uncertain intention, the provider may consult with or refer the patient or legal guardian to trusted moral advisors provided by the Catholic healthcare organization, the (arch)diocese, or the National Catholic Bioethics Center.⁸ Such advice seeks to guide both the provider and patient or legal guardian in achieving moral certitude about the patient’s intention in taking a PGT.

3. PARENTS OF A CHILD WITH DOWN SYNDROME OR OTHER GENETIC CONDITIONS: PASTORAL POST-TEST COUNSELING

Receiving the news of having a child with Down syndrome or other genetic condition can be very challenging. Parents may experience anxiety, fear, sadness, or even depression. Catholic healthcare organizations should offer post-testing counseling to those parents who receive abnormal test results; this counseling should include but is not limited to:

- a) A list of psychological and social support services.
- b) Literature, websites, and videos on the challenges and blessings of having a child with Down syndrome or other genetic condition.⁹
- c) Information about support groups and associations such as *Be Not Afraid* (benotafraid.net) .
- d) Arrange a one-session dialogue with a parent(s) of a child with Down syndrome or other genetic condition.
- e) Recommend a session with a spiritual counselor (priests, religious, chaplain, minister, etc.).

⁸ See: ERD 37: “An ethics committee or some alternate form of ethical consultation should be available to assist by advising on particular ethical situations, by offering educational opportunities, and by reviewing and recommending policies. To these ends, there should be appropriate standards for medical ethical consultation within a particular diocese that will respect the diocesan bishop’s pastoral responsibility as well as assist members of ethics committees to be familiar with Catholic medical ethics and, in particular, these Directives.”

⁹ See: Mary O’Callaghan. "Down Syndrome: On Holy Ground." *The Catholic Thing* (March 18, 2010).

[Catholic Healthcare Organization Logo]

[Name of Catholic Healthcare Organization]
[Address of Catholic Healthcare Organization]

Patient Name:
Date of Birth:

EXPRESSION OF INTENT REGARDING PRENATAL GENETIC TESTING

[Name of Catholic Healthcare Organization] is a healthcare ministry of the Catholic Church. As such, we witness to the sanctity of life from the moment of conception until natural death. The Church's defense of life encompasses the unborn and the care of women and their children during and after pregnancy.

Prenatal testing and diagnosis are permitted when the mother indicates she will not terminate the pregnancy even with an undesirable result, the procedure does not threaten the life or physical integrity of the unborn child or of the mother, and the procedure does not subject them to disproportionate risks.¹⁰

Prenatal testing and diagnosis are not permitted at [Name of Catholic Healthcare Organization] when undertaken with the intention of aborting an unborn child, whether because a serious defect is detected, the child's sex is not desired, or for any other reason.¹¹

I have been offered information and resources on the medical conditions that might be detected upon testing. I also understand the policies regarding Prenatal Genetic Testing at [Name of Catholic Healthcare Organization], and consequently:

- I decline a Prenatal Genetic Test at [Name of Catholic Healthcare Organization].
- I am taking a Prenatal Genetic Test at [Name of Catholic Healthcare Organization / or elsewhere], and I am not undertaking this Prenatal Genetic Test with the intention of aborting my child.

Signature of Patient (or a parent/legal guardian if the patient is under 18)

Date & Time

¹⁰ United States Conference of Catholic Bishops, "Ethical and Religious Directives for Catholic Health Care Services," (6th edition), 2018, No. 50.

¹¹ Ibid.