Prenatal Diagnosis of Lethal or Non–lethal Conditions and Disability

12th in the Series of Webinars Produced by the National Catholic Partnership on Disability

Webinar Panel

Moderator:
- Dr. Marie Hilliard, Director of Bioethics & Public Policy, The National Catholic Bioethics Center

Presenters:
- Dr. John Bruchalski, OB/GYN, Founder of Tepeyac Family Care Center
- Fr. Dan Mindling, OFM Cap., Academic Dean & Moral Theologian, Mt. St. Mary’s Seminary
- Tracy Winsor, Parent Support Specialist, parent
- Monica Rafie, Founder of BeNotAfraid.net, parent

Communicate with the Panel

To ask questions of panel members by computer:
- Write your questions in the space provided at the bottom of your screen
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Litany for Life

Let us pray...

Lord have mercy...

Litany response:
R. Lord, you give us life.

The baby is born without the diagnosed disability or anomaly

Medical decisions are required immediately after birth

Ongoing medical treatment and pastoral support required

The baby may die at or before birth

The parents, in the face of great confusion and moral error at the time of the prenatal diagnosis consent to abort their child
Post-abortion Ministry

- Project Rachel
- Rachel's Vineyard
- Lumina

Lumina - a ray of light in abortion's darkness
abortion, after abortion, pain, shield, healing after abortion, women's rights, healing after abortion.

Purpose of Webinar

...To increase sensitivity by providing personal perspectives of parents who have carried to term

...To provide you with ministry models and resources

Support for stillbirth, miscarriage & newborn death

Elizabeth Ministry

See Webinar Toolkit at www.ncpd.org; do a Google search for more information.
American College of Obstetricians and Gynecologists suggests all women should be offered screening tests before 20 weeks of pregnancy.
Testing can have value when used to plan the safest delivery possible of a child with a condition that needs specialists.

Non-routine Prenatal Testing

Screening vs. Diagnostic Tests

- **Screening**: provides a statistical probability of the presence of a disability or anomaly
- **Diagnostic**: more conclusively identifies – nearly 100% – presence of a condition
  - Some tests involve risk of miscarriage (1 in 700 to 1 in 100 cases)

Do parents understand the purpose and risks of prenatal testing?

Absolutely NOT—in too many cases.
Move from Fostering Health to Preventing Birth

There is a move to “prevent” the birth of a baby with a disability or disease...

- OB/GYN is sued 4–6 times in career
  - belief in the “perfect outcome”
  - unreal expectation that prenatal medicine is perfect
- Parents report feeling harassed or judged if they consider carrying to term
  - Asked repeatedly to affirm their decision not to abort

“Poor” or “Adverse” Prenatal Diagnosis

- A diagnosis that is considered “incompatible with a long life” expectancy
- Often involves “quality of life” judgments
- Today’s Prenatal Diagnosis—the “birth defects” of past generations

Each human person has dignity...

Created in God’s image
Gift of the Heavenly Father

In the eyes of God, the child diagnosed with an underdeveloped brain, as in the case of anencephaly, is of incomparable worth, full human dignity, a child of God like every other child.
PLEASE…

“Always use respectful words—there is no reason to strip the baby of his or her dignity.”

Most prenatal diagnoses end in abortion

My cousin with Down syndrome once asked me if he was an endangered species.

I had no words for him.

“Incompatible with Life”

- Source of great pain for parents
- Not a medical term.
- Termination offered even though there were medical options available for our baby, which we did pursue
D-Day

- Always remember “diagnosis day”
  - Shell shocked
  - Everything changes
  - Offered abortion before even knowing medical options

  *From that day, the pregnancy does begin to feel more like a battle than something wonderful.*

The Child is Alive Now

- The parents have a relationship to their child now
  - Their very seriously ill child is both their child and a child of God right now
- Every moment becomes precious

  *We are children of God now, what we will later be has not yet been brought to light.*

(1 Jn.3)

Confusing Language...

- Merciful choice
  - which is neither for the unborn child

- Induce labor
  - mother may think it is a needed step to save child while intent of doctor is to end the life of the child
Distancing Parents from the Decision

Abortion vs. carrying to term leads to very different reactions, and levels of pain and peace.

either path has pain, …in choosing to cherish the precious time we were given with Hailey Grace... we have been changed forever. Lisa, Hailey Grace's Mom

Informed Consent

- A good decision in conscience demands that couples understand the facts and options
- Withholding medical information = poor medical care
- Seek alternative medical care and advice

Couples in this situation are victims of a doctor who is deciding for them.

The Catholic Church Teaches...

- Prenatal testing is not permitted when undertaken with the intention of aborting an unborn child with a serious defect.

When they do not involve disproportionate risks for the child and the mother, and are meant to make possible early therapy … these techniques are morally licit.

Evangelium vitae
Are Some Tests Inherently Illicit?

“Testing is always immoral when it is done with the mindset that if the tests reveal unwanted characteristics, disabilities or anomalies, parents will abort.”

Parents Need to Know...

- abortion is not an acceptable response to prenatal testing
- your doctor’s purpose for testing is probably different than your own
- screening tests and diagnostic tests provide different information
- invasive tests, including amniocentesis have increased risk... maybe even disproportionate risk.

Medical Perspectives

- Misguided compassion—belief that suffering would be less if the child was not allowed to live
- Concern with litigation such as wrongful birth lawsuits
- See abortion as good medicine, and a “necessary evil”
Societal Impact When Carrying to Term

Parents often face:
- feelings of isolation, being ignored and judged
- the need to reaffirm their decision as new diagnoses arise throughout the pregnancy
- awkward questions or stares that speak loudly from the providers or the nurses involved, “Why are you doing this?” or “Are you sure you still want to do this?”

Are Parents Receiving Sufficient Information?

- It is not uncommon for mothers who have terminated to note that they had not understood carrying to term was an option
- Most women look only to their provider rather than speaking to other women who have made the choice of carrying their child to term

Fearing the Financial Burden

Many parents fear the possible cost of medical care or raising a child with a disability

Is not the lack of resources a social justice issue?

As a society, we must find a better way of meeting needs than killing the child.
From the *Catechism of the Catholic Church*

“Prenatal diagnosis is morally licit, ‘if it respects the life and integrity of the embryo and the human fetus and is directed toward its safe guarding or healing as an individual.’” (§2274)

... and Church Teaching

And further, “... It is gravely opposed to the moral law when this is done with the thought of possibly inducing an abortion, depending upon the results:

A DIAGNOSIS…MUST NOT BE THE EQUIVALENT OF A DEATH SENTENCE.”

(CDF, *Donum Vitae* I. 2.)
First, parents came to our ministry post-abortion following a prenatal diagnosis, often only understanding that it was an abortion after reading that word on the hospital bill.

Secondly, parents came following a stillbirth or newborn death.

*We learned...all parents experiencing a prenatal diagnosis need options and better support.*

Common Themes Shared by Parents

- a need to make quick decisions
- worse and worse news at each appointment
- lack of support among family and community
- diagnosing physician will typically offer abortion
Common themes, cont.

- Often end up choosing abortion because they have been convinced that:
  - their baby will suffer
  - their marriages will fall apart
  - their other children will be badly affected

Tepeyac Family Center Belief

- Our approach is maternal.
- When we know that we have a sick child, we don’t separate ourselves and the parents from the child through abortion.
- The best place for a sick child is close to the mother

Support

- There is no research to support the assertion that terminating is easier for the mother.
- Parents who are given practical and ongoing support when the baby is going to die express feelings of gratitude and peace.
- Local services like Dr. John’s clinic, Isaiah’s Promise, and Be Not Afraid, Charlotte, are really crucial in the Church’s first response to these parents.
Healing Following Abortion

- Healing ministries offered by Church such as Project Rachel
- Our greatest source of healing—the Sacraments

“God the Father of Mercy, has sent the Holy Spirit among us for the forgiveness of sins….Through the ministry of the Church, may God give you pardon and peace, and I absolve you ….”

The Larger Community of Faith

We must become equally good at offering:
- support and encouragement at the time of diagnosis
- clear moral teaching at the time of decision making
- presence and prayer in the event of still birth
- support and understanding throughout pregnancy
- help to parents in raising their child

Applying Moral Teaching

I’d like to see a Catholic pastoral response that is equal to our phenomenal Catholic teachings.

- Offer comfort and support throughout the pregnancy and beyond
- An ongoing crisis—not “Mission Accomplished” following decision not to abort

We need REFERRALS that are timely, complete and sensitive.
5 Practices for Pastoral care at the time of diagnosis

- Take Time
- Connect with the Baby
- Reframe the Details
- Offer Resources
- Follow up

Caution in Searching for Services

- Look for consistency in Catholic teaching in materials used and resources recommended. Consider all sources:
  - Conferences, programs, websites, flyers, publications
- When recommending resources always monitor new editions
- Recognize that Catholic ministry around perinatal loss and secular services around perinatal loss are not the same thing.

Make Referrals Early

- Statistics indicate, these very situations end in abortion, SO referring early is very important.
  - At the first indication that baby may have a problem
Permission to Contact

- Referring agencies should ask parents for permission for us to contact them.
- Then first contact is done by our initiative rather than relying on the shocked or bereaved parents to reach out to us.

At the end of the call, they are no longer alone.

Online Outreach

Support Through Perinatal Hospice

- Perinatal hospice offers a welcome alternative to abortion.
- Kristen Anderson Perinatal Hospice Program
  - spiritual and psychological comfort while meeting the individual medical needs of each mother and her sick child
  - a continuum of support from the point of diagnosis to one year after
Peer Ministry in Charlotte

- Effective service development is first and foremost about finding sensitive, caring volunteers.

- “I didn’t realize you are a regular service... I just thought that these parents had the best friends in the world.”

Action Steps

- Educate others
  - Share information you’ve learned today

- Ask questions of yourselves
  - Assess parish or diocesan readiness to support parents with a prenatal diagnosis

- Begin planning
  - Form a core group
  - Explore the toolkit

Faces of Dignity
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- For a replay of this and archived webinars
- Select a webinar under the “Webinars” navigation button and scroll to the bottom of the page to access the Toolkit Resources
- Download transcript and PowerPoint
- Order the webinar on DVD—available late October

Special thanks to our major funders...

- Knights of Columbus
- Our Sunday Visitor Institute
- Warren P. Powers Charitable Foundation

...without whom this webinar would not have been possible.
NCPD in Partnership with:
- USCCB Secretariat of Pro-Life Activities
- USCCB Department of Justice, Peace and Human Development
- The Catholic University of America
- Archdiocese of Washington
- National Council of Catholic Women
- National Apostolate for Inclusion Ministry