

Transcript of National Catholic Partnership on Disability Poor Prenatal Diagnosis October 5, 2010

Vcall
601 Moorefield Park Dr.
Richmond, VA 23236

Phone: 888-301-5399
Fax: 804-327-7554

info@vcall.com
www.vcall.com
www.investorcalendar.com

Participants

Dr. Marie Hilliard, Director, Bioethics and Public Policy - National Catholic Bioethics Center
Dr. John Bruchalski, OBGYN, Founder of the Tepeyac Family Care Center
Fr. Dan Mindling, OFM Cap., S.T.D., Academic Dean of Mount Saint Mary's Seminary
Tracy Winsor, Parent Support Specialist, Co-founder, Be Not Afraid, Charlotte
Monica Rafie, Founder of BeNotAfraid.net

Presentation

Dr. Hilliard:

Welcome everyone both here in our live audience as well as those participating through the streamed and webinar format in sites throughout the United States. A reminder to everyone in group sites to please silence your cell phones at this time. I am Marie Hilliard Director of Bioethics and Public Policy at the National Catholic Bioethics Center. As a registered nurse with graduate preparation in Maternal-Child Health, I recognize the importance of this topic today, prenatal diagnosis of lethal or nonlethal conditions and disabilities from numerous perspectives. Such a diagnosis is commonly referred to as "poor prenatal diagnosis", but throughout this webinar we will use the abbreviated term prenatal diagnosis. We also wish to clarify that we will be focusing solely on the child in the womb, not on conditions which might also jeopardize the health of the mother.

We have brought you experts imminently qualified to address this issue from a healthcare provider, theological and pastoral and most importantly a family perspective. Welcome also to our presenters on our panel Dr. John Bruchalski, a practicing obstetrician and gynecologist, as well as founder of the pro-life Tepeyac Family Care Center; Fr. Dan Mindling, a Capuchin priest, academic dean of Mount Saint Mary's Seminary in Emmitsburg, MD, and a moral theologian; and two parents who have devoted themselves to addressing the support needs of families faced with these challenges — Tracy Winsor, Parent Support Specialist and co-founder of a local service supporting parents carrying to term in the Catholic Diocese of Charlotte, and Monica Rafie, Founder of BeNotAfraid.net.

Appreciation goes to all of the partner organizations who have collaborated with NCPD to make this webinar and its Toolkit possible. They will be named individually on a slide later in the program, but we wanted to thank them and mention their contributions at this time. And we welcome representatives from our partners who are with us today in the audience here in Washington, D.C.



You will be able to submit questions in writing to the panelists as part of this webinar. If you are sitting at your computer, note at the bottom of your screen, a space for you to enter questions and then click 'submit'. If you are at one of the many large groups convened across the United States or if you are attending live with us today at The Catholic University of America, you can submit written questions to a moderator, who will submit them to the panelists.

Let us begin with prayer. We welcome his Excellency, Bishop Francisco Gonzalez, Auxiliary Bishop of the Archdiocese of Washington to lead us in our litany.

Bishop Gonzalez:

Good afternoon. Let's begin by praising the Holy Trinity. In the name of the Father, and of the Son, and of the Holy Spirit. Amen. Let us invoke the Lord's presence on our gathering as we consider the needs of some of the most vulnerable and fragile among us, the infant in utero and at birth. Please join in the responses. For those who fail to protect them, let us pray: Lord, have mercy.

All: Lord, have mercy.

Bishop Gonzalez:

Christ, have mercy.

All: Christ, have mercy.

Bishop Gonzalez:

Lord, have mercy.

All: Lord, have mercy.

Bishop Gonzalez:

Now we pray the litany for life. The response will be, Lord you give us life.

All: Lord you give us life.

Bishop Gonzalez:

You breathed life into Adam.

All: Lord, you give us life!

Bishop Gonzalez:

You formed Eve from flesh.

All: Lord, you give us life!

Bishop Gonzalez:

You created us in your own image.

All: Lord, you give us life!

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Bishop Gonzalez:

You filled Sarah's barren womb.

All: Lord, you give us life!

Bishop Gonzalez:

You gave Abraham a son.

All: Lord, you give us life!

Bishop Gonzalez:

You made the infant, John, leap in Elizabeth's womb.

All: Lord, you give us life!

Bishop Gonzalez:

You nourish the vulnerable and weak.

All: Lord, you give us life!

Bishop Gonzalez:

You are the divine comforter.

All: Lord, you give us life!

Bishop Gonzalez:

You are the Life that is the light of all.

All: Lord, you give us life!

Bishop Gonzalez:

You are the bread of Life.

All: Lord, you give us life!

Bishop Gonzalez:

You have the words of eternal life.

All: Lord, you give us life!

Bishop Gonzalez:

You are the resurrection and the life.

All: Lord, you give us life!

Bishop Gonzalez:

You are the Way, the Truth, and the Life.

All: Lord, you give us life!

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Bishop Gonzalez:

Father, we pray for the grace to love, respect and protect all human life, from conception to natural death. We ask this in the name of Jesus, our Lord. Amen.

Dr. Hilliard:

Thank you, Bishop González. We are happy to have you with us today.

There are a number of ways in which the scenarios of parents who received a prenatal diagnosis unfold: The baby is born without the diagnosed disability or anomaly or medical decisions are required immediately after birth, some concerning beneficial versus excessively burdensome treatment which may include life saving surgery or procedures. A disability is present that will require ongoing medical treatment and pastoral support, or the baby may die at or before birth. The baby may be presented in such a scenario in which the parents, in the face of great confusion and moral error at the time of the prenatal diagnosis, consent to abort their child. We recognize that within these varied situations some parents have received good moral counsel and others have not. We extend our condolences to all who have lost a child. There are real opportunities for the Church to provide improved support, comfort and care to the parents who have or may have in the future experienced a prenatal diagnosis. Often abortion has been presented as the only option to many parents, who later are left with great sadness. The Church reaches out in healing through Project Rachel, Rachel's Vineyard and Lumina to those who have experienced abortion. Some dioceses and/or local parishes reach out to those who have lost a child to miscarriage, stillbirth and newborn death through such healing support as Elizabeth Ministry. This work provides an important witness to the dignity of all life, no matter how brief. As such, we encourage the development of this important Ministry in all communities as a source of comfort to parents experiencing perinatal loss.

Please note that the webinar toolkit, available on NCPD's website at ncpd.org, this website provides pastorally sensitive materials so that parents with varying experiences and needs can be directed to the best possible resources. Our intention in this webinar is to increase sensitivity by providing you with the personal perspectives of parents who have carried to term. The PowerPoint program will provide numerous pictures of parents and their families and these infants. We would like to extend our deepest appreciation to all the parents who have shared their stories and pictures with us for this webinar in the hopes that they will help you better understand this area of ministry. These parent's stories and images are enlightening and compelling, and so we share them now and show an explanation of the two pictures chosen to help promote this webinar on the NCPD flyers. We are going to start with a maternity photo as we share the story of this baby's life. We think it is a good story with which to introduce this topic, a case study, as it were, because it is pretty typical as prenatal diagnosis stories go. Tracy.

Tracy:

This belly belongs to the first mom we served in our ministry in North Carolina, and the precious little person in that belly is Baby Hailey Grace. The pregnancy began as most do with joy and excitement. The first couple of months were uncomplicated as her parents looked forward with anticipation to a 17 week ultrasound at which they

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would be told whether they were expecting a boy or a girl. It was supposed to be a wonderful day, but instead of “congratulations,” for the first time, they would hear the words “incompatible with life.” And they left in tears. More testing followed, with news that grew only more grim. Hailey Grace had Trisomy 13 (a genetic syndrome) with two significant heart defects, and a brain malformation which resulted, in her case, with facial deformities. Her parents, however, were relentless in not only wanting to carry her to term, but also in making certain that they understood the nature of the various diagnoses and the treatment options that might be available for her, were she to survive to birth. It was at one such consult that a doctor who seemed especially perplexed with their unwillingness to abort finally said to her mother, “I question your ethics. You just don’t get it. This is a throw away baby.” I will always remember the day Hailey Grace’s mom called me on her way home from that appointment to tell me that story for it provides a sad insight into the nature of the judgment that can be attached to a prenatal diagnosis. It surely impacts even today my desire to see that parents carrying to term find the support they need. Now I know what everyone wants to hear, at the end of a story like this, is that Hailey Grace was born and survived. She did not. The second picture we used on our webinar flyer and that NCPD also has on their website is a photo of Hailey Grace’s mom holding and embracing her wonderful daughter, born premature and still. The doctors were right about Hailey Grace’s heart and her brain and her sweet little face, but they were never right about her dignity. One need only see the faces of those who welcomed and held her in silence on the day of her birth at 32 weeks gestation to know that she was never a “throw away.”

Dr. Hilliard:

Thank you, Tracy, for that compelling real-life story. We’ll continue with an explanation of prenatal testing. We have seen such an evolution in what is available to parents as they try to address the health needs of their baby before birth. Dr. John, what tests are routinely given in any pregnancy at this time?

Dr. John:

Your geographical area, the resources that you have access to, and the professional training of your healthcare providers will ultimately determine what tests are done routinely and when during the pregnancy. Our American College of Obstetricians and Gynecologists (ACOG) suggests all women should be offered screening tests before the 20th week. Since all screening and diagnostic tests have false positives and false negatives, integrated or “sequential screening tests” are ideally recommended.

Dr. Hilliard:

Under what conditions are non-routine prenatal tests encouraged?

Dr. John:

Well those non-routine prenatal tests are encouraged based on many factors: whether you have twins, previous obstetrical history, family history, availability of early detection ultrasound, recommendation by a geneticist or a high risk OB doctor, or the need to have a definitive diagnosis and not just a numerical risk for those who provide abortion, to make the decision for an earlier abortion. In our practice, which is thoroughly pro-life, we sometimes use Invasive diagnostic testing to plan the safest

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delivery possible of a child with a condition that needs specialists at a referral hospital rather than the community hospital where we usually deliver.

Dr. Hilliard:

What is the difference between a screening test and a diagnostic test?

Dr. John:

Dr. Hilliard, a screening test indicates a statistical probability of whether a child will be born with one of the several genetic syndromes or other atypical conditions. A diagnostic test is more definitive, often nearly 100%, in confirming the presence of a specific condition. Now diagnostic tests are the amniocentesis or chorionic villus samplings or CVS. These are more invasive, and they carry with them miscarriage in unborn children on the order of 1 in 700 to 1 in 100 cases. Some parents chose not to have invasive tests because once they are fully informed of those risks, they choose not to have them.

Dr. Hilliard:

And are parents receiving accurate information on what is considered a confirmed diagnosis, verses an indication of a diagnosis based on a screening test?

Dr. John:

I believe that most parents are receiving accurate information, but statistical risk is a very difficult idea to wrap your hearts and souls around when considering if your child is affected by one of the conditions mentioned or a disability. At the first mention of a problem, whether through a screening or a diagnostic test, the parent is fearful and anxious. That has been my experience. It is only human nature to imagine the worst. From our perspective, that of a doctor, it is painful to have to inject doubt into the joyful expectation of family.

Dr. Hilliard:

We have a flyer in our toolkit from ACOG on "Prenatal Tests During Pregnancy" that can be downloaded by our participants. But, Dr. John, do expectant parents understand the purpose, and most importantly the risks of prenatal testing?

Dr. John:

Absolutely not, in too many cases. I still today have patients that were "routinely" given a screening test, and they received an adverse level, and were then told they needed to do an invasive procedure to confirm the screening test. Moms want to take care of their unborn children; they want to make sure they are healthy. A test that doesn't jeopardize the wellbeing of their child is often accepted. However, in a significant percentage, the realities of what the answer from the screening test gives are not thought through.

Dr. Hilliard:

Have we seen a move from using such testing to foster the birth of a healthy baby to prevention of the birth of a baby with a disability?

Dr. John:

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Yes we have. Today, the OB/GYN is sued on the average of 4-6 times in their professional career. Because of the belief in the “perfect outcome,” and the unreal expectation that prenatal medicine is perfect and all adverse outcomes should and can be detected and predicted with very few surprises, and the reality of the law suit based on “wrongful birth,” there is a move to “prevent” the birth of a baby with a disability or disease. Many moms are declining the screening or diagnostic test, one or more times, and yet they continue to be asked by the healthcare providers of the practice, “Are you sure of your decision?” which is then documented in the chart multiple times. Many patients feel harassed or judged if they even consider bringing into this world a child with a disability, or the desire to accept what God gives rather than finding out before the delivery occurs.

Dr. Hilliard:

And now we consider prenatal diagnosis. Such a diagnosis is sometimes referred to as “poor” or “adverse.” Dr. John, could you please speak to this?

Dr. John:

A poor prenatal diagnosis is simply a diagnosis that is considered incompatible with a long life expectancy either during the gestational period, while the child is living in the mother’s womb; or after the umbilical cord is cut, and the child is outside the womb. It can also be used to indicate a child whose life is judged by cultural standards as not worth living due to decreased mental capacity or significant physical or biochemical illnesses and abnormalities. Today’s prenatal diagnosis, poor prenatal diagnosis, is the “birth defect” of a generation or so ago, if identified prenatally because we have the tests to do so.

Dr. Hilliard:

What is the significance in the use of the words “poor” or “adverse” when attached to a prenatal diagnosis, and how do the use of such terms impact advocating for those whom society has judged not to have a high “quality of life”? Fr. Mindling, would you please begin.

Fr. Mindling:

The idea that life has value only when it has a particular quality misunderstands the concept of human dignity. The ground of our dignity as human persons is that we are created in the image of God, sustained by His Grace, redeemed by the sacrifice of Christ, and called to eternal happiness with Him in heaven. None of these are achievements of our own; they are gifts of our Heavenly Father. Human dignity is a given, an endowment which entails a divine command: RESPECT HUMAN LIFE. A prenatal diagnosis does not change the dignity of life. In the eyes of God the child diagnosed with an underdeveloped brain, as in the case of anencephaly, is still of incomparable worth, still has full human dignity, a child of God like every other child. Monica, what has been your experience as a parent?

Monica:

Well I would say the words “poor” and “adverse” are extremely hurtful to parents, and in a lot of instances the doctors really don’t know what the outcome will be—they can make their best educated guess, but all they can offer is a prognosis. I can say this—doctors never need to tell parents that they have a “throw away baby” or as one mom

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told me, a "doorknob." Medical professionals please remember that even if you believe the prognosis is terrible, always use respectful words —there is no reason to strip a baby of his or her dignity.

Dr. Hilliard:

We are aware of statistics indicating that 90% of unborn babies diagnosed with Down syndrome will be aborted, and in England a study indicated 86% of those with neural tube defects such as Spina Bifida will be aborted (Kristol Study). Furthermore, one study indicated that 92% of women enrolled in prenatal care would consider abortion (Kavanaugh Study). Dr. John, how many pregnancies with a prenatal diagnosis result in an abortion?

Dr. John:

Most. We live in a society that expects no illness, nor imperfections. These numbers are accurate. My cousin with Down syndrome once asked me if he was an endangered species. And I had no words for him.

Dr. Hilliard:

Oftentimes doctors justify such abortions by stating that the child's condition is "incompatible with life." Is this truly a medical term, Dr. John, and how damaging is this term to parents who receive that diagnosis of their unborn child's condition?

Dr. John:

No, it is not a medical term, but an emotional, and psychological and physiological one. Monica, how do parents react to that phrase?

Monica:

"Incompatible with life" is a well-known phrase among many parents who have had a prenatal diagnosis. When they talk about the impact of those words, it's with a great deal of pain and resentment. Remember, most parents go into their 20-week ultrasound to find out the sex of the baby and they hope to come home with a cute ultrasound picture for their refrigerator, but instead they are shell-shocked with the very out-of-the-blue-news that there is something very wrong. Everything has changed for them—the defining moment of the pregnancy is no longer the due date, but diagnosis day. A lot of us call that day "D-day"—because from that day on the pregnancy does begin to feel more like a battle than something wonderful. The phrase "incompatible with life" points to one presumed outcome—and it's reserved for the worst types of diagnoses. These are conditions that many of us would not ever have heard of before, such as anencephaly or potter's syndrome, but sometimes even conditions that could be survivable, such as Trisomy 13 and 18 and complex heart defects or other genetic syndromes. Now, in my own case, when I was pregnant with my second child, my daughter Celine, the phrase "incompatible with life" was used by our regular obstetrician, about her. It turned out that there were options available for our baby and we did pursue those as soon as she was born. Celine is now nine years old. But, we were offered termination before we even knew what our medical options were.

Dr. Hilliard:

Tracy, do you have anything you would like to add?

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Tracy:

Yes. As much as I would argue that the words “incompatible with life” are damaging to parents, sometimes the reality that a baby will not survive the pregnancy and/or birth is true. There is a misperception that only those parents whose babies live will feel positive about the experience of carrying to term. Sadly that supports the notion that the experience of abortion is easier is somehow easier than that of perinatal loss. Increasingly research suggests the opposite.

Dr. Hilliard:

Fr. Mindling, can you speak pastorally to the confusion associated with the phrase “incompatible with life”?

Fr. Mindling:

When a doctor tells a parent that the child has a condition incompatible with life, it is pastorally important to help the parent understand that the child is alive right now. That the parents have a relationship to their child now, and that their very seriously ill child is both their child and a child of God right now. St. John reminds us, “We are children of God now, what we will later be has not yet been brought to light.” It is also important that a prognosis which says this child is not likely to live long after birth is met with a promise of compassion and accompaniment, of support and of prayer. When doctors tell anyone that we only have a little time, every moment should become precious.

Dr. Hilliard:

Other language used by the medical profession might be confusing to parents and pastoral staff as they seek to make moral decisions. Increasingly we see the use of euphemisms to make what in our hearts and moral code is unacceptable, acceptable. If the fetal diagnosis is a fatal diagnosis, we hear terms such as “merciful choice,” which is neither for the unborn child. And, in fact, such a choice also robs the parents of the opportunity to walk with their child until natural death. Mothers are often told that they should undergo an “early induction of labor.” While the mother may consider this a needed step to save their child from suffering, the intent of the doctor may be to end the life of the child. That does not mean, however, that there are not morally appropriate early inductions of labor, to remove, for example, a diseased placenta threatening the life of both the mother and baby, even before the baby is viable. Such details are beyond the scope of this discussion, but our toolkit contains more specific information on such scenarios. Dr. John, are parents who receive a prenatal diagnosis with recommendation for early “induction of labor” aware that the “induction of labor” is generally in this case an abortion?

Dr. John:

It is the elephant in the room. From my experience as a doctor who at one time did abort these affected children, we wanted the parents to distance themselves from their decision to purposefully shorten the life of their child and used words to describe the abortion that would help them do that. I think most do know the reality but they try to skirt that. But having been at the bedside of parents who aborted and those who carried to term, I witnessed very different reactions and levels of pain and peace. It is a hard reality for a parent or a doctor to admit that they could not take care of a sick

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child, and actively ended that child's life. I have seen this choice to end life early lead to depression and other marital problems.

Dr. Hilliard:

Fr. Mindling, do you witness confusion, and later guilt as parents believe they should not contradict medical advice, and agree to abortion?

Fr. Mindling:

Yes. Couples are overwhelmed with the complexity of the medical information, and sometimes make bad decisions thinking they are following the doctor's recommendations. It is completely understandable that parents turn to medical professionals to understand what is happening to their child and what choices can be made. Trusting professional medical advice makes good sense, but one must also recognize that doctors give expert advice about medicine, not about morality. Sometimes the lines are crossed as when judgments on the quality of life are being made, and abortions are recommended. All too often these decisions are made very quickly after diagnosis. Parents sometimes say afterwards that they felt pressured to do something that they now regret.

Dr. Hilliard:

Fr. Mindling, when asked for counsel, how can a priest point to concerns regarding informed consent if they suspect that the medical information received by the parent is incomplete?

Fr. Mindling:

A good decision in conscience demands that couples understand the facts and the options they have. If physicians do not present all the options to the couple, including the options which respect the life and the dignity of their unborn child, couples are not being given good medical care. Couples in this situation are victims of a doctor who is deciding for them. No couple should be pressured into an abortion, or be led astray by confusing terminology or language such as "give your baby back to God." If this is happening, the couple should seek alternative medical care and advice.

Dr. Hilliard:

What is the position of the Church regarding prenatal testing?

Fr. Mindling:

Prenatal testing is not permitted morally when undertaken with the intention of aborting an unborn child discovered with a serious defect. Prenatal testing is permitted when the procedure does not threaten the life or physical integrity of the unborn child or the mother and does not subject them to disproportionate risks; when the diagnosis can provide information to guide preventative care for the mother or pre- or postnatal care for the child; and when the parents, or at least the mother, give free and informed consent. So which tests are licit? *Evangelium vitae* says, "When they do not involve disproportionate risks for the child and the mother, and are meant to make possible early therapy or even to favor a serene and informed acceptance of the child not yet born, these techniques are morally licit."

Dr. Hilliard:

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Are there any tests that are inherently illicit?

Fr. Mindling:

Testing is always immoral when done with the mindset that if the tests reveal unwanted characteristics, disabilities or anomalies we will abort this baby. Monica, please give us your thoughts on this.

Monica:

It's true there are parents who go into testing with the mindset of intending to abort. However, mostly we see parents who are caught up into a whole process that moves them along without requiring them to make definitive decisions about the purpose of the testing being done, yet, all the same, serves to move them toward termination. Most begin the process saying they will not abort. And yet we know that most who begin that process and receive a prenatal diagnosis actually do abort. Tracy, did you have any thoughts?

Tracy:

These are the points that should be stressed to parents: abortion is not an acceptable response to prenatal testing; and secondly, your doctor's purpose for testing is probably different than your own; screening tests and diagnostic tests provide different information; and lastly, invasive tests, including amniocentesis have increased risk, maybe even disproportionate risk.

Dr. Hilliard:

A study by the American Congress of Obstetricians and Gynecologists indicated that 90% of respondents justified abortion for fatal fetal anomalies, and 63% justified abortion for nonfatal anomalies. What do you think is the motivation of medical providers for recommending abortion on such a routine basis, Dr. John?

Dr. John:

I believe the motivation of the medical profession is threefold: one is misguided compassion with the belief that both patients —parent and unborn child — would suffer less if the child was not allowed to live; secondly, the reality of lawsuits for wrongful birth are a daily issue in our profession; and thirdly, many medical professionals believe that abortion is good medicine in certain situations, a "necessary evil" so to speak.

Dr. Hilliard:

Tracy, what is the impact on care for parents choosing to carry to term following a prenatal diagnosis, given the bias of abortion as the preferred management of these situations?

Tracy:

Because most parents choose to abort, doctors often don't know what to do with parents who decide to carry to term. Parents report feeling everything from isolated or ignored to judged, and our local service often provides support to parents as they navigate the medical community during the pregnancy and beyond. We help them identify questions and write birth plans and seek appropriate consults. And often the decision to carry to term is made several times during a pregnancy especially if a

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medical provider is not supportive or if additional complications are noted. Dr. John, what has been your experience?

Dr. John:

In a society that talks about “choice,” Tracy, when it comes to their poor prenatal diagnosis, choice is given lip-service because you are expected to abort your affected child. Most parents who carry children to term with disabilities get that awkward question or stare that speak loudly from the providers or the nurses involved, “Why are you doing this? Don’t you know the suffering you will cause your child and your family?” Abortion is the stressed option and the one most taken because another way is not presented. Parents will choose abortion or termination which will be offered as “early induction of labor,” “medical interruption of pregnancy” or just “saying goodbye early.”

Dr. Hilliard:

Dr. John, are parents receiving sufficient information in order to give informed consent around prenatal testing and carrying their baby to term?

Dr. John:

I suspect not. It is not uncommon for moms who have terminated to note that they had not understood carrying to term was a real option. Perinatal hospice programs are not very common yet. Cold statistics are not easily translated into understanding of what this diagnosis entails. Most women do not speak to other women who have made the choice of carrying their child to term. Rather, most women look to their provider or their pastor to give the answer to what they would recommend in this situation, to help them make a good decision.

Dr. Hilliard:

Fr. Mindling, what have parents shared with you?

Fr. Mindling: Sometimes we hear concern from families wondering if they can handle the possible cost of medical care or raising a child with a disability. They fear that adequate resources will not be available for their child. But isn’t this really a matter of social justice? As a society, we must find a better way of meeting needs than killing the child.

Dr. Hilliard:

And Father, how do you as a seminary professor make the Church’s teaching clear to students?

Fr. Mindling:

Seminarians study the Church’s teaching in a required course in moral theology and medical ethics. They study the catechism of the Catholic Church which is clear regarding abortion, affirming it as a moral evil and it has been referred to as such since the first centuries. It further notes that “Prenatal diagnosis is morally licit, ‘if it respects the life and integrity of the embryo and the human fetus and is directed toward safe guarding or healing the fetus as an individual.’” 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 of testing. No diagnosis should ever be the equivalent of a death sentence.” In addition, seminarians need pastoral experience to

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prepare them to minister to families facing this crisis such as these. I have them read Madeline Nugent's work, *My Child My Gift: a Positive Response to Serious Prenatal Diagnosis*. The text gives them access to concrete cases. Likewise the text of *For the Love of Angela* by Nancy Mayer-Whittington has been helpful. It documents not only the story of the short life of Angela, but of the role of the priest, himself a graduate of Mount St. Mary's, in ministering to her parents. Ordering information on these books is available to webinar participants on our resources page. I also recommend the "Pastoral Notes Regarding Crisis Pregnancy Issues Related to Genetic Defect, Fetal Anomaly, or the Health of the Pregnant Woman," developed and distributed by the Pro-Life Office/Pregnancy Help of the Archdiocese of Boston. These Pastoral Notes, again found in the webinar toolkit, provide guidance to pastors and those who provide pastoral care in parishes and health care settings, to address the complicated and challenging problems faced in parishes and in health care facilities seeking to respond compassionately to parents who have received a prenatal diagnosis.

Monica:

Fr. Mindling, I would also like to recommend another book, *Waiting for Eli: a Father's Journey from Fear to Faith*. It was written by a father whose son was prenatally diagnosed with spina bifida. Also we have included a pastoral care flyer from Be Not Afraid in the toolkit which can be helpful as well.

Dr. Hilliard:

Tracy, share with us what led to the founding of the local service with which you work in the Diocese of Charlotte.

Tracy:

As volunteers in perinatal loss ministry, my co-founder and I were encountering parents who had experienced a prenatal diagnosis usually in one of two scenarios. At first, they would come to our ministry post-abortive, often within weeks of the abortion, still trying to figure out and process the frenzied pace of how they got from being a prenatal diagnosis to an abortion. They were often confused by the language used around what they had done, often seeing the word "abortion" for the first time when it came on the billing information they received from the hospital. Their babies were always named and because these are the only post-abortive women handed a baby, they would sometimes say things like, "I knew I had made a mistake when they handed me Cecelia." Their grief seemed particularly complicated to us and research certainly indicates that that observation was accurate. That is why appropriate support at diagnosis is so important, as is access to sensitive post-abortion support ministry.

In the second scenario, we were encountering parents at the time of a stillbirth or newborn death realizing as they shared their stories with us that they had known about the lethal anomaly prenatally, but often didn't know how to share that news. My co-founder was in just that position having carried to term with a diagnosis of a genetic syndrome, never telling anyone before his birth that Baby Casey was not expected to live.

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What we learned from these encounters, was that parents experiencing a prenatal diagnosis need options. And that the roughly 20% of those who carry to term on their own, doing exactly what we would expect them to do in valuing life, deserve better support. It is our responsibility as Church to provide pastoral care and works of mercy to those in crisis. And frankly, we must claim these babies if we do in fact believe, and want to demonstrate through our actions, that every life is sacred. Monica, what have you learned from the parents you serve?

Monica:

If you read any of the stories on BeNotAfraid.net, you will find common themes shared by the parents: a need to make quick decisions, worse and worse news at each appointment, lack of support among family and community, if the news has even been shared with them. The diagnosing physician will typically offer abortion and we know that they are legally obligated to inform the parents that abortion is an option. But typically these are not parents who went into prenatal testing with the idea that they would abort their baby if he or she were not perfect. Rather, they are parents who never dreamed something could be wrong, never thought through what they would do if an amniocentesis showed their baby had this or that. They often end up choosing abortion because they have been convinced that their baby will suffer if they don't, or that their marriages will fall apart if they do have their baby, or that their other children in the family will be badly affected by having a medically fragile, or in some way disabled, sibling.

Dr. Hilliard:

So often abortion is mischaracterized as a solution, when, in fact, it creates a whole other set of issues for parents. Are such issues addressed, Dr. John?

Dr. John:

Abortion is never good healthcare. Though many medical personnel argue that the best way to cope with an adverse fetal diagnosis is to deliver the baby before survival is likely, we are committed in our practice at the Tepeyac Family Center to the belief that such a decision equates to an abortion. Ironically, this course of action, having the abortion, often creates greater long-term suffering for all individuals involved. The solution becomes another problem. Our approach is maternal. When we know through prenatal diagnosis that we have a sick child, we don't separate ourselves and the parents from the child through abortion. Every mom wishes to remain close to her child when he or she is ill, and the best place for a sick child to be is close to the mother. The "hospice" of our program is the mother's womb where she can be with the child providing for 100% of the child's needs until that child is ready to face the world or to face heaven. We support the mom and family in their decision with special care up to one year following that birth.

Dr. Hilliard:

Monica, is there any truth to the notion that ending a pregnancy early of a child that is almost certain to die, is easier than carrying to term?

Monica:

No, Dr. Hilliard, there isn't. There is no research to support the assertion that terminating is easier for the mother. Research does tell us that the grief is as intense

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as the grief experienced around other perinatal losses, and it has the potential to cause complicated grief surrounding the trauma of the event of the abortion. Parents, who are given practical and ongoing emotional support when the baby is going to die, express feelings of gratitude and peace. That's why local services like Dr. John's clinic, or Isaiah's Promise, or even Be Not Afraid in Charlotte, are really crucial in the Church's first response to these parents.

Dr. Hilliard:

Fr. Mindling, what should parents do if they are listening to us now regretting an abortion?

Fr. Mindling:

I would hope that parents would avail themselves of the healing ministries offered by the Church, such as Project Rachel, which you mentioned earlier, Marie. And of course our greatest source of healing, the Sacraments, cannot be underestimated. The Project Rachael Manual offers many practical helps to Confessors. It can be found in our toolkit; I recommend it highly. Imagine the healing of the aborted woman whose sorrow is met with the voice of Christ in the Sacrament of Reconciliation as she hears: "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 from your sins."

Dr. Hilliard:

What are the larger costs to us as communities of faith Monica?

Monica:

If you look around in your parish, which is an otherwise welcoming and inclusive community, and you don't see children with Down syndrome or other disabilities, be assured that you need this ministry. If those children are not present, more than likely a large number of the "missing ones" are among the 80-90% of those aborted when identified prenatally. Fr. Mindling?

Fr. Mindling:

We are good as a community in helping with the grieving process, of supplying rituals and prayers after the death of the child. 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, and support and understanding throughout the pregnancy. We must become better at being there to help parents who carry special needs children and who lovingly give them birth and raise them.

Dr. Hilliard:

Monica, from your perspective as a parent and service provider, what application would you like the Church to provide on its moral teaching?

Monica:

I would like to see a Catholic pastoral response that is equal to our phenomenal Catholic teachings. We need to understand that a prenatal diagnosis is a crisis and that there is a need to move toward offering parents true Christian care or as Tracy's

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bishop, Most Rev. Peter J. Jugis, calls it. And when you do that we can be confident that we have offered a truly Catholic response. We should offer comfort and support throughout the pregnancy because this is an ongoing crisis. We don't back away just because a family is resolute in deciding not to abort. We don't say therefore, "mission accomplished"! The decision not to abort didn't end the crisis. In fact, in my own personal experience our crisis pregnancy didn't end until months after the birth of our daughter because we gave birth to a medically fragile baby. We spent the first month in the hospital. We were isolated a long time after that and then we were back in the hospital for an urgent procedure, we had a few months of calm, then another surgery, and recovery from the surgery, and so on. And we were watching for it and dealing with developmental delays, then yet another surgery. And we had it relatively easy compared to many, many families. Now the good news is that we in Church ministries already know how to do this. We recognize the need for supportive services for moms who continue traditional "crisis pregnancies" through programs like Project Gabriel. Now we need the same awareness of what is required to support parents experiencing a prenatal diagnosis and carrying to term. We can do this with the help of some already existing ministries, such as Elizabeth Ministry, or Project Gabriel and there are existing post-abortion programs should likewise ensure that they have adapted to become responsive to the unique needs of parents who did abort around a prenatal diagnosis. But in the areas where those types of ministries are not available, a new, organic growth of this type of outreach needs to occur. Dioceses should be proactively cultivating responses at the diocesan level or encouraging the development of parish level groups. Our webinar toolkit on the NCPD website is meant to help with this work. The fast-moving nature of these situations requires that we provide referrals that are timely, complete and sensitive to Catholic ministry ideally but sometimes to other community-based services as well.

Dr. Hilliard:

Monica, I know that you have specific suggestions to offer based on your work with families.

Monica:

Well two years ago, Tracy and I developed a brochure on pastoral care for parents experiencing a prenatal diagnosis. We do have five practices that we recommend. The first is take time. Listen. Make sure the parents feel heard and understood. And as we respond to them, we ourselves need to understand the diagnosis. Is it a screening finding vs. a diagnostic finding? Is it a lethal condition vs. non-lethal condition? Does the baby have Down Syndrome and a secondary diagnosis such as heart issues? Third, you need to connect with the baby. This is how we can help parents reconnect. So we want to keep the baby present tense. We want to use the baby's gender in the way we speak to the parents such as saying, "your sweet boy" or if the name has been given, we want to use the baby's name. We want to offer blessings and prayers for the baby; and we want to make sure the parents understand that the relationship that they have with their baby is very different from the one the doctors have with the baby. Fourth, we want to reframe the details. We want to affirm the parents in their shock and grief because they have lost the baby that they thought they were expecting. We want to educate them about male and female grief and we want to offer them our care as bereaved parents. We want to encourage them to slow down. They should not be rushed into making decisions. We want to remind them

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that they have a responsibility to parent to the best of their abilities even now. We want to remove abortion euphemisms gently and check to see if they have been advised regarding the option of carrying to term. We want to find out if perinatal hospice has been offered to them if it's an appropriate option in their situation. And we want to assert that any early good-bye is not the easy way out. We want to offer resources. Let them know they are not alone. Offer local support if it's available. Offer Benotafraid.net. The toolkit on NCPD's website will have lots of resources available. Explain Catholic teaching on the issue. And assure them of your availability moving forward. Make sure you have an emergency number where they can reach you. And finally, you really want to make sure you follow up within 12-24 hours ideally. Now, remember these situations are changing. They will have results from follow up tests that will be coming in, the baby's status maybe changing and you really need to remain engaged in their situation. Tracy, I know you must have some things to add to this.

Tracy:

An interesting point to note as you look at these five practices is that not only are they effective at the time of diagnosis, but they point to what a local support should be for parents carrying to term. For example, ongoing support is a ministry of presence. It is about "making time" for these parents through the pregnancy to listen and be available even for the birth if need be. Connecting with the baby, reframing the situation and offering resources is about helping the parents move past the diagnosis to the reality of the precious baby entrusted to them. It's about helping them find joy and meaning during the pregnancy and at birth as they parent this baby to the best of their ability. And lastly, "follow up" in on-going support means remembering. Developing as it were a supportive relationship around the details of this baby and this pregnancy, and making certain that parents prepare for the birth of this baby and for whatever life lies beyond.

Dr. Hilliard:

What a challenge you issue! It appears that our usual approach through crisis pregnancy centers is not necessarily sufficient when there is a prenatal diagnosis crisis. Monica, can you tell us why?

Monica:

Sure. Crisis pregnancy centers do not typically see these moms: they go from obstetrician, to maternal specialist, to an abortion. Therefore if we want to reach parents who have received a prenatal diagnosis, we have to be more creative, and smarter in our outreach. In my own experience and based on the reports of other mothers, the medical community will refer to supportive services where they exist. But those in the medical community don't typically perceive the traditional crisis pregnancy center as an appropriate referral in these situations. Now because of how Be Not Afraid is named and because of the language used on the website, it has been listed in places that a crisis pregnancy center typically wouldn't be such as on genetic counseling websites and resources and in addition maternal fetal websites and resources.

Dr. Hilliard:

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There are many prenatal and perinatal parent support resources that can be identified through a Google search. We are focused for this webinar on resources that are consistent with Catholic teaching. When parishes and dioceses are searching for pastoral tools and ministry resources, what are some words of caution that you would be able to share with our participants, from your experience Tracy?

Tracy:

Consider this, because they created a new category of perinatal loss organizations called medical interruption of pregnancy, perinatal loss organizations have been serving women who aborted following a prenatal diagnosis for years and well before we in the Catholic community even recognized the need for special support for these parents. In this regard, we do have to play catch up both in our perspective and in our service. In Charlotte we found that we have to be very careful in what resources or services we use or recommend. We check the bereavement materials we provide with every new printing and sometimes we find new sections, new lines, new paragraphs and sometimes new chapters have been added. And also we have learned to be come very careful with referrals recognizing that Catholic ministry around perinatal loss and secular services providing perinatal loss support groups for instance, are not the same thing.

Dr. Hilliard:

Earlier Monica indicated that referrals for parents with a prenatal diagnosis should be timely, complete and sensitive. Can you speak to that, Tracy?

Tracy:

Yes. We suggest that referrals be made early, at the first indication that there is a problem with a baby, recognizing that the crisis begins then and that from that point on, abortion is a possibility. Sometimes we find referrals are not made early because the word abortion hasn't been mentioned; or parents are only asking for prayers; or parents aren't perceived as the kind of people who would consider abortion; or those who would refer are reluctant to do so because they don't want to "overwhelm" parents. Often, as the statistics indicate, these very situations end in abortion, so referring early is very important. Secondly, we suggest that referring agencies or individuals ask parents for permission for us and our service to contact the parents as opposed to the parents being given our contact number. In this way, it is our initiative that results in a first contact and no one is relying on the shocked or bereaved parents to reach out to us. Where local Catholic peer ministry exists, a referral results in a call to the parents, which creates for them immediately community around the crisis of prenatal diagnosis. At the end of that call, they are no longer alone, someone else has been right where they are, and carried to term before them.

Dr. Hilliard:

Monica, you established the first Catholic on-line outreach for parents. What are the plusses of on-line outreach?

Monica:

The benefit of having an online outreach is first of all that we are where the parents are. I know from my own experience that the first thing you do in this era of technology is you come home from that awful diagnosis experience and you go online looking

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things up. So when parents Google for this or that condition, they will pull up a story from our site. Now the way it really works the best is when parents find us and then we are able to refer them to a direct referral to local help such as BNA Charlotte. We recently helped a mom who was new to her community, but has now developed life-long friends she'd never have met otherwise who were there for her when her baby boy, Andrew Benedict, died. These friends held her baby.

Dr. Hilliard:

We know that the availability of comprehensive, on-going support will help parents who have received a prenatal diagnosis and choose to carry to term. We have two local service providers here, one medical with Dr. John and one community-based peer ministry in the Catholic tradition with Tracy. How from your experiences can local parishes, dioceses, and communities develop services that meet the needs you each have identified and are meeting in your communities? Would either of you care to respond?

Dr. John:

Once we offered our perinatal hospice to the community, many other health care providers and many patients were relieved that there was an option other than abortion. Over these last forty years, when abortion became the practical solution to the problem of the identified unborn sick child, we as medical professionals have all experienced that many patients are not helped by being forced into doing a procedure that is physically, medically, and spiritually repulsive. Much as hospice has helped integrate suffering and illness and death at the end of life, perinatal hospice has done so when that suffering and illness is identified in the womb. Health is based on the relationships found in community, and using the perinatal hospice approach builds community by reinforcing medicine as an act of life affirming mercy and promotes the initial community, the mom and the unborn. Our Kristen Anderson Perinatal Hospice Program (KAPHP) is a program of the Tepeyac Family Center designed to provide a multi-disciplinary approach to pregnant women, their babies and their families as they await the birth of their child who has received a life-threatening diagnosis. It exists to provide pregnant women and the person most intimately involved with their child, spiritual and psychological comfort while meeting the individual needs, medical needs of each mom and her sick child. The program offers a continuum of support from the point of diagnosis to about one year after. Tracy, what would you like to add to this?

Tracy:

When we started our peer ministry in Charlotte, we were essentially two mothers who knew something about pastoral care and loss ministry and by way of research had developed a concept of care, what we would do to provide support to parents carrying to term. We were also blessed with a little money and a supportive priest. We didn't have a website; we didn't have brochures; we didn't have a doctor, but we knew what parents needed and having had our own experiences of carrying to term or loss, we thought we could make a difference and we have. The service that we provide, though not medical is comprehensive and we are listed on the national perinatal hospice website. In our own development and in our experience sistering services in other dioceses and mentoring lay ministers in other states, we have found effective service development is first and foremost about finding sensitive, caring volunteers. You need some formal training and some guidelines that address things like

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confidentiality, but your ministry may still be forming even as you serve your first parents. I think a nurse at one of our births best summed up our service at Be Not Afraid, Charlotte when she said during a recent birth, "I didn't realize you all are a regular service. I just thought that these parents had the best friends in the world." And that's kind of how it always is as we see our Charlotte ministry growing and developing with new volunteers and new partnerships and new ideas about how to bring comfort and healing to families carrying to term. We've come to realize that we learn something from every family we serve and we are changed by every baby we welcome.

Dr. Hilliard:

Before we move to Questions and Answers, let's spend a few minutes identifying action steps for those listening. Let's review what we can all be doing. We can...

1. Educate others. Share with them the information and resources you have been given today.
2. Ask questions of yourselves. Is your parish or diocese equipped at this time to support parents with a poor prenatal diagnosis to carry to term?
3. And begin planning. Think about people you know who would be interested in forming a core group and explore the toolkit with them. In our toolkit you will find an expanded list of action steps that we recommend dioceses and parishes consider in trying to begin or expand services to families who receive a poor prenatal diagnosis. Please review these resources and plan your Action Steps.

And now in closing, each panelist will share their recommendations on how to serve and support parents who receive a poor prenatal diagnosis such as those pictured in these slides.

Dr. John, what action steps do you recommend your colleagues in the medical community take?

Dr. John:

One, remember that we care for two patients and please, please use language that dignifies both. Secondly, inform yourself about the perinatal hospice through our toolkit and other resources and provide a healthy option for the family confronted with a poor perinatal diagnosis. Make it your community's own. They will thank you. And thirdly as Catholic healthcare providers, if any of this information penetrates your heart you can contact us at the By Mercy.org or the Tepeyac Family Center.com. And remember at the core of social justice and good medicine is the Gospel of Life.

Dr. Hilliard:

Fr. Mindling, what action steps do you recommend for your priests and deacons?

Fr. Mindling:

I recommend that they prepare themselves to address the needs of the families, in three short steps. Step one, be familiar enough with the churches pro-life teaching to bring it to bear on their situation and compassionate enough to speak the truth in charity. Offer ethical guidance. Such guidance can't be morally neutral. Secondly, become informed enough about biology to understand what the parents have been told, and what implied or explicit advice they are likely to receive. And thirdly, learn about the experiences of those who have ministered with couples through reading

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such books as My Child, My Gift by Madeline Nugent, and when possible, talk with parents with personal experience of a prenatal diagnosis. They are a ready faculty for the ongoing formation of priests, deacons, and laity.

Dr. Hilliard:

Tracy, what action steps do you recommend to others who want to start support efforts for parents who receive a poor prenatal diagnosis?

Tracy:

First I would say go to the resources available in the NCPD toolkit. And secondly, educate yourself regarding perinatal loss and bereavement which is a very important aspect of this work. Third, talk to other local providers. Many of us are available to mentor you in your efforts to serve parents and you can reach out to us through the toolkit. Fourth, don't overcomplicate your effort. Serve the parents that God sends you and don't waste your time creating resources on materials are already available. And lastly, honor confidentiality. It is a privilege to be entrusted with the precious details of a baby's life.

Dr. Hilliard:

Monica, what action steps do you recommend?

Monica:

Really I think all the panelists gave excellent steps. They reminded me of a dad from my own diocese coined the term "prenatal diagnosis SWAT Team," claiming that the Church needs such teams to be ready for the kind of crisis that a prenatal diagnosis can bring. He's right that we need to be proactive in addressing the crisis of abortion at the prenatal diagnosis of lethal or non-lethal condition or disability. But, speaking as a woman, and a mom, and in fact, a mom who has had a prenatal diagnosis experience, I would probably temper the SWAT Team idea a little bit. But making a "SWAT Team" that is trained to intervene with compassion and sensitivity in the prenatal diagnosis crisis is a good place to start.

Dr. Hilliard:

Thank you all for your very helpful guidance. Our live audience and those engaged through the webinar have submitted questions that I will attempt to direct to the appropriate panelist. Remember, if you are sitting at your computer, note that at the bottom of your screen, there is a space for you to enter questions and click 'submit'. You can still send them in and we will respond to as many as time allows. We do have many questions. You can also submit them to our moderators here who will be looking them over to see for redundancy and submitting them to us.

The first one that I have I think is going to be addressed to Tracy. You advised caution in prenatal resources. What types of things should you look for in terms of what would be a good resource? This is from a priest who is actually in the live audience.

Tracy:

When you are looking at perinatal bereavement materials you want to look for any sections that address difficult decisions that families have to make or any suggestion

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of a medical interruption or saying good-bye early. There are some very popular books that have added sections, even whole chapters that address the specifics of a parent's experience who feels positive about terminating around Down Syndrome. So you can usually find these things associated with some kind of an idea that parents around the loss had a difficult decision to make or the wording medical interruption of pregnancy or saying good-bye early. Also careful with referrals to organizations are very common in the city I am in, Charlotte, for support groups for parents who have had a stillbirth to also include parents who have terminated around a prenatal diagnosis in those support groups for parents that have had stillbirth, so there's a lot of mixing.

Dr. Hilliard:

As a follow-up to that and it could either be Tracy or Fr. Mindling, how important it is to coordinate those resources with your local diocesan offices.

Fr. Mindling:

The resources that are available can be easily coordinated through the diocesan pro-life office or family ministry office. Each diocese has a slightly different arrangement, but there is no reason to reinvent the wheel and certainly no reason for a pastor to feel they have to become an expert on every possible question. There are resources in the diocese and to evaluate these particular kinds of resources that you might come across we also frequently have Catholic hospitals and Catholic professionals and others in your parish who you may know are experienced in these particular areas of ministry. Parish priests should not get himself to feel overwhelmed when there is tremendous help available if he looks for it.

Dr. Hilliard:

The next question is not assigned to anyone. I think it probably is something I should answer because it's related to abortion statistics and then I will have Dr. John follow-up. The question is are there research studies, is there data available on the statistics of abortions in terms of children with anomalies either fatal or not. And we have in our toolkit some studies that are there and also in the script with the statistics we give which will be available online we will put in brackets the authors of that research so that is available to you. Dr. John did you have anything you wanted to add to that?

Dr. John:

No. I think those statistics are very accurate and it's definitely part of my own experience having been on both sides of this issue.

Dr. Hilliard:

The next question on the screen here is one that is not directed to us. We don't have an expert here who is representing the particular hospitals throughout the country either non-Catholic or Catholic so we are not able to respond to that in terms of what is being done in particular hospitals in terms of the unborn child with such a diagnosis, but I think in terms of the local experience, Dr. John perhaps, is it hospital specific be it a Catholic or non-Catholic hospital in terms of how that response would be?

Dr. John:

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I work at a non-Catholic hospital and there is definitely a realization that there is a piece missing. Perinatal services, services that try to bring healing to a very difficult situation are occurring more and more. Most labor and delivery units have people designated to try and bring that together and I believe that through the experience of watching more and more people carry their child to term, I believe that that experience will affect the medical community and so each hospital right now is working through that on their own.

Unidentified Speaker:

Marie, could I add something?

Dr. Hilliard:

Please.

Unidentified Speaker:

We are sistering a service in the Catholic diocese of Charlestown which is all of South Carolina and there are several Catholic hospitals there which have a partnership with an existing perinatal hospice service so we certainly look forward to the development of additional supportive services within our Catholic institutions.

Dr. Hilliard:

Thank you. This is a question for Fr. Mindling or Dr. John. Prevention of child suffering is often cited as reasonable motivation for abortion. Putting aside the great value of redemptive suffering and speaking only from the standpoint of medicine, does the child in utero or after birth experience physical suffering as a result of the most common anomalies?

Fr. Mindling:

Dr. John perhaps you could address the physiological question.

Dr. John:

Sure. Each child is an individual. Each child has its own capacity to receive inputs to handle its pain and suffering. We have found in our experience that these children are not suffering because of the love that they have received from their parents and the supportive network around them. Father.

Fr. Mindling:

I think the Church's teaching about suffering is directly related to respect for life. It is often asked just exactly what is the euthanasia movement in our country and euthanasia is defined by the church as killing to prevent suffering. This understanding helps us I think to get at the core of the question. We neither do a preemptive strike against suffering. Our model here I think is the Blessed Mother who witnessed the suffering of the most innocent and the sufferings of Christ who was there with compassion and understanding and faithfulness at that particular site. Every Catholic hospital should have crucifixes around so that we know what it is we are doing when we accompany people who face the challenge of bearing suffering. But killing is not a solution to end suffering.

Dr. Hilliard:

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The next question speaks to the accuracy of testing and what is the frequency of a missed diagnosis in terms of either a confirmative diagnostic test or a screening and I think we should send that to you Dr. John.

Dr. John:

Sure. In that sequential analysis of the noninvasive testings, the quad screen has a detection rate regarding Down's syndrome of about 80-81 percent. It has a false positive rate somewhere between 5 and 7 to 10 percent. When you have that first trimester combination of where you combine a high-level ultrasound with some biochemical tests and that raises the detection rate to about 86-87 percent, still with a 5-7 percent false positive rate. That means that if they say there is a problem there but in actuality there is not. So when you do the sequential testing and bring it all together, the data is such that we can find about 95 percent of Down Syndrome children and once again that false positive rate is still about 5 to 7.5 percent.

Dr. Hilliard:

As a follow-up overall, I know this is specific to different types of diagnosis and we don't have that kind of detail, but in terms of an anomaly, what are the percentages of pregnancies before or even after an abortion that there would be an anomaly?

Dr. John:

Well the anomalies can range from an extra digit and sadly in my life, I have terminated a pregnancy because of an extra digit. I sadly also terminated a pregnancy because the mother was so overtaken by the statistic, she was at a certain age because the tests are age-specific and the incidence of the tests went from one in 4,000 for her age to about one in 2,000 even though her husband was comfortable with that she was not. So I went ahead and helped them abort that child. So my experience is of that and I believe that if you look at all anomalies it is 3-4 percent of all births.

Dr. Hilliard:

I think that Doctor John would be the first to add with great regret.

Dr. John:

Oh absolutely. Thanks for God's mercy.

Dr. Hilliard:

One of our questions that came through the web, and I think it's a very good one, are there other faith communities that share our perspective on the sanctity of all human life from conception and by that we mean fertilization to natural death. I think this is yours Fr. Mindling.

Fr. Mindling:

I wish I could claim to be an expert on what all believe. But I think that many share and look to form coalitions with the respect life programs that are offered in Catholic health care facilities and Catholic programs throughout. We have tremendous networks of support among many of the Christian communities and non-Christian communities within the United States. We are not alone in this. What makes our particular perspective useful is that we offer the strength of a sacramental system and

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we offer the strength of a strong Catholic community committed to the support as part of our outreach and belief in the Gospel of life. I think there are no other communities of faith, of which I am aware that have the tremendous amount of documentation and documents so powerful as Evangelium vitae and all can gather around and share and enjoy the light of the Gospel message that those documents contain. We are called upon to exercise leadership in this area.

Dr. Hilliard:

As a follow up and perhaps Tracy or Monica have some insight into this. Is there something that makes a mother or parents, mother and dad more vulnerable to making that decision for an abortion? And perhaps Dr. John also might have some understanding of what background would lead one in terms of resources perhaps or understanding of human life would lead to that decision.

Tracy:

Well I think a failure to think through the process that you are entering into and to sort of blindly step onto the carousel not knowing what direction it will lead you does make parents vulnerable and they are usually not expecting the first diagnosis and then with some conditions there will be other diagnosis throughout the pregnancy that complicate the baby's prognosis. So I think the first thing that a parent would want to do before consenting to any prenatal testing is to understand this is going somewhere. Do you want to step on this express train? Are you ready for the information that you can receive? So I think a failure to make informed decisions would make anyone vulnerable to making a bad decision. That falls within their responsibility. Medical providers can assist by giving complete information, not pushing toward a certain outcome. Certainly you can read your patient. If your patient does not want to talk about termination, stop. So I would say sensitivity on the part of medical providers can help lessen the vulnerability. And being responsible for the information that you are collecting when you receive -- when you consent to prenatal testing is another way to diminish -- to prevent a vulnerable position.

Dr. John:

I also think from the medical point of view we have been bombarded with technology over the last 40 years. We are bombarded by information over the last 40 years. Research and technology. I truly believe that there are Catholic doctors, Christian doctors, men and women of goodwill who are beginning to see the deficit in what is really compassionate, complete care. And along with people like the Pathos (ph) Project, I think there are mentors across the country stepping out and really reaching out to the next generation of healthcare providers to give them the tools they need to meet people like Monica and Tracy.

Dr. Hilliard:

As a follow-up to that this came through one of our sites, are persons who do not have a good command of English in terms of receiving medical advice more vulnerable or are those who are here in this country and perhaps lacking health insurance or resources are they more vulnerable?

Tracy:

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I think that if the case is true that language can be confusing for a parent for whom English is their primary language, then there are complications associated with English not being your primary language. And I think the other thing we are seeing in North Carolina is that if parents lack the resources to pay for additional testing, the more expensive testing, the diagnostic testing then they are being encouraged to terminate around the screening test when in fact, they don't even really know what the diagnosis might be so I think they are in fact moved more quickly toward abortion.

Dr. Hilliard:

The next question is asking about resources in terms of videos. Of course, our webinar will be available, and we will talk about that as I close, on line for you. But our resources such as videos and we have no one on the podium here representing the US Conference of Catholic Bishops but they have marvelous resources. They are one of our partners, our sponsors, co-sponsors and they have marvelous resources on our webpage, but does anyone know of any other resources available to help persons, videos we are talking specifically about, to help persons who are facing such decisions?

Tracy:

Lots of parents have put up videos on YouTube is one example. There are other video providers on the Internet as well. If you are serving a parent, I would suggest that you view the video first and you think about the message that is inspiring the video. I would not suggest just randomly sharing videos, but you can look up by diagnosis, there are some beautiful videos that parents have put up of their own children with Down Syndrome, spina bifida and really any diagnosis you can think of. There are parents out there who have shared the joy that they feel having their children in their lives.

Fr. Mindling:

If I could add, I think that one of the pastoral things worth mentioning is that don't just hand people resources. You really need to view the resource, learn the resource, make the personal contact and help the couple make contact and reconnect with their child. It's a very personal ministry. I think sometimes we might be tempted to use tools, but the tools need somebody to handle these tools and that makes a significant difference pastorally. There are a lot of materials that can be put out but personal contact is crucial.

Dr. John:

And that supports our belief that health is based on those relationships found in community. It goes beyond the video, the technology. It's that one and one care and discipleship.

Dr. Hilliard:

That's a nice follow-up to that Dr. John. There's a question here both from the live audience and through the webinar. In terms of the preparation of medical students and nursing students for these crises, what type of – or is there any type of organized preparation or is all requiring medical students required to perform abortions as part of their training.

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Dr. John:

We are beginning to develop an outreach called Medical Students for Life which is also reaching out to the healthcare community in general at the educational level. Many facilities offer abortion training and it is assumed that you will participate. Most of them are upfront about it. They will tell you ahead of time in their packets and brochures and information that if you come here you are expected to go along. However, some they offer it and they still respect your right to conscience. And so I think by educating young people who really feel called to go into medicine. This is a vineyard. This is – we need laborers in the field here in order for us to integrate and really make that net more solid and so this new outfit coming out of I believe Students for Life which is Medical Students for Life will start doing that.

Dr. Hilliard:

I know that there are many students who call us at the National Catholics Bioethics Center. We have a 24/7 hotline where for anyone who is facing any type of a health-care crisis or dilemma in terms of the moral analysis from again IVF right through to palliative care. It's a resource that is available to persons. We are online and our phone numbers listed there also. So we are a resource, but many times we are getting calls now from persons in the healthcare professions with their questions and a number of them have gone to pro bono legal defense groups to protect religious liberty. There are a number of groups out there, the Live Defense Fund is one of them, St. Thomas Moore. There are a number of them out there that do provide assistance, much of it pro bono for those challenges.

Dr. John:

Marie, I think added to that is this also has to be modeled meaning to contact the people who are doing it and asking those questions. That's what we are trying to do in medicine. We have even gone the extra step of going nonprofit to try to raise money within the community so the community takes care of its own so to speak.

Fr. Mindling :

If I could add I think that the disability communities can be very easily overlooked resource because when we are talking about asserting and affirming the dignity of people who have difficult diagnosis, we need to recognize that there is a whole group of people in the church advocating for justice for people who have disabilities and this justice not only concerns the unborn child with a prenatal diagnosis but programs that extend far beyond that. And these can have influences on the people who provide medical care for people with disabilities and the training necessary to address the needs of this population can also be advocates with us.

Dr. Hilliard:

We had a similar question that just came in from the United Kingdom about the role of persons with disabilities who are adults in helping the entire community understand the needs as well as specific families. I know personally an adult woman who has Downs Syndrome who has a college degree and is working as a teacher's assistant in a school in which she provides assistance to children with special needs so clearly there is a roll.

Tracy:

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If I could add all of those parishes which are addressing the needs, special needs within their parish community are testifying to parents who are considering carrying to term a child with special needs that this is possible so we cannot underestimate the witness of our work in this area.

Dr. Hilliard:

I think this has to be our final question. We ran a little later than we had anticipated because we started a little later, but I guess the last call is for you Father and this is a question that we discussed ourselves yesterday and it's an important question. What about when a priest gets called by a family that is going to abort their child and wants the child baptized.

Fr. Mindling:

First of all, I think we have to understand that we have two different people concerned at this moment. We have the child with every right in the world to pastoral care, we have the parents who are caught in a terrible dilemma. The parent who asks to have a child baptized is already recognizing that this is a child with dignity, a child whose life should be respected. And I think pastorally it's very appropriate for a priest at that time to provide clear, unambiguous, ethical advice that says that the very reason why you want your child baptized is the reason why you should not be acting against the life and dignity of your child. At the same time, I want to always reassure people that the ministry to those who have made the tragic choice of abortion is not coming into the presence of the priest so that we can condemn you, but that we can offer the ministry of reconciliation to those who in the light of their sorrow seek to be fully healed of the problems that have been brought about by this mistake. That door remains always open.

Dr. Hilliard:

Thank you to all our wonderful panelists. We want to thank all who have participated both in our webinar and in our live audience here. Your interest and your commitment truly is inspiring. We want to continue to support your efforts in the following ways because we understand that resources are important to your efforts.

This webinar, as I said earlier, will be available on-line within two weeks at the NCPD web site, ncpd.org, and will be there for one year for viewing in replay. It will be available on DVD by the end of October of this year. Check our website to make sure that it is up there and you can make that timely purchase for a number of your programs this coming fall. Our script and our PowerPoint will be available on the NCPD website. Information about materials, documents or other things we have recommended is in our Toolkit, which will be updated on a regular basis. Download and use those materials, it's certainly accessible to you and you will find it helpful. Some of the questions which you raised to which we did not have time to answer you can find resources there that will help you. You can always contact original sources like the NCPD and ourselves.

We wish to thank our major funders: the Knights of Columbus, Our Sunday Visitor Institute, and the Warren P. Powers Charitable Foundation. And those who are in partnership with the NCPD, our webinar partners: the USCCB Secretariat on Pro-Life Concerns which has been very, very supportive, as well as the USCCB's Department

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**Transcript:
National Catholic Partnership on Disability
Poor Prenatal Diagnosis
October 5, 2010**

of Justice, Peace and Human Development, both of those offices incredibly supportive as well as the wonderful support of the National Council of Catholic Women, the Archdiocese of Washington, and the National Apostolate for Inclusion Ministry. And certainly a special thanks to The Catholic University of America for hosting our live broadcast of this webinar and all of the technical support which they have provided. We need to let you know for our efforts to continue your support and the support of people you know is needed. We welcome support. We are a voluntary agency and, of course, that support would always be welcomed so we can continue to serve all persons, both those who help the vulnerable as well as the vulnerable themselves.

An evaluation will come up next on your screen and we ask you to fill it in online or at your group site. It will be available online for another ½ hour. The Vcall site will automatically close at this time. Thank you, again, on behalf of the panelists and the NCPD. And especially for the panelists.

[applause]

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