

TESTIMONY
BEYOND MEDICINE

RIMINI MEETING PREVIEW



Everyone Stop: He's Here

ELVIRA PARRAVICINI, a New York neonatologist and founder of the first hospice for terminal newborns, will be among the guests at the Rimini Meeting. In a field that negotiates the fine line between euthanasia and unnecessarily prolonged artificial life support, the hospice professionals cherish life, whether it lasts three minutes or three months. Here she explains that beauty "happens," and that, in following it, "one never errs."

BY ALESSANDRA STOPPA



Everyone is in the operating room: doctors, interns, and nurses. The birth of Siamese twins is rare, and so there are also students ready to take pictures. Then, there is the father, a 15-year-old African-American wearing a bandana on his head and rapper jeans. His girlfriend is on the bed, a 15-year-old like him, ready for the C-section. They never had any doubts: “They’re our daughters.” What was there to understand or decide? They knew from the beginning that the daughters would live only a few minutes, because they are attached at the chest, with one heart, and it is impossible to save them. The delivery begins in the midst of a flurry of white scrubs and recriminations. Most think this should not have been done, “because it will scar them for the rest of their lives; they should have aborted, and been done with it. It’s absurd,” they insist, grumbling to the end—until Keela and Kayla are born, embracing each other, each weighing a pound and a half. Their boy-father asks, “Can I hold them?” and begins to cuddle them. They are barely breathing. “I’m here, don’t be afraid. Daddy is here...” Silence fills the room. Nobody moves. Tears flow down a few faces. “Such a powerful beauty was manifesting itself that everyone in that room was changed. We contemplated the beauty of the Mystery,” says Elvira. This expresses everything needed to explain her neonatal hospice, a place that cherishes that beauty, bends over it and cares for it, for as long as possible, for all the time of the life of a child, be it three minutes or three days; a few hours or few months.

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“WHY DON’T YOU GO TO AMERICA?” It is not a ward, exactly. It is a special delivery room, prepared when and as it is needed. Recently, the hospital also financed preparation of a little room where parents can spend the time given with their child. It is a fascinating time “for all of us, also for the nurses, because it requires everyone to



Elvira Parravicini (right) and Teresa, a nurse at the clinic, looking after a baby in comfort care.

Dr. Elvira Parravicini, a neonatologist at Columbia University in New York, will speak at the upcoming Rimini Meeting about the program she founded to assist newborns affected by fatal syndromes: babies born already terminal. It is the first of its kind in the world. Everywhere else, if these children are allowed to be born, they are born to die. Here, instead, they are born to live. “Existence has a beginning and an end. We do not establish the times, but in the meantime we can do everything possible to make their lives beautiful.”

engage humanly,” says Elvira. “Techniques are not enough.” Comfort care for newborns does not have a model; it is not theorized about and she did not study it in books. Asked where she learned it, she smiles and says, “From my mother.” She says understanding the need of the other depends on how you look at him or her. “I have learned a gaze. I saw it in my mother and in the companionship of the Movement.” There is no protocol, just what she calls “cornerstones.” It calls one to “respond to the primary needs of a child”—the need to be welcome, which means being with those who love him/her, the need to not suffer hunger or thirst, the need to be warm. “These things give the baby great relief.” And the way she says this shows the fullness of her gaze. In the name of these cornerstones, all the rules of intensive care go out the window. “You do things that shouldn’t be done, even ‘crazy’ things, but you do them because the care is highly personalized. It depends entirely on the baby. We depend on him to let us know.” They even went so far as to perform a small



operation on a newborn with amniotic band syndrome, whose head and face were distorted. “You saw only a little hole, and that was her mouth, with which she needed to eat and breathe. We put in a little gastric tube to help her. In this way, she lived her four months, but breathing well.” All the decisions are made with the parents. “You decide the care step by step, make a proposal, compare ideas. They help you a great deal, because those who opt for comfort care are focused on the baby, not on their own pain. They want to serve the baby’s life.”

One night, Elvira was called for an emergency. A mother she was following, whose child had Trisomy 18, a life-limiting congenital syndrome, delivered early. She was there, in the commotion of the emergency room, with everyone working and without a room. “It took a tremendous effort to enable her to stay with the child in a suitable place.” A battle, as if to say: stop, everyone. He is here. Perhaps comfort care is primarily this stopping, this respect for the fact that someone new is there. “They >>>

THE MEETING PRESENTS ITSELF TO THE WORLD

Rome is the final stop on a tour of public gatherings and cultural evenings to offer a foretaste of what will happen at this year’s Meeting of Rimini.

The official presentation of the 33rd Meeting of Rimini took place on Wednesday, June 6th, in Rome. The Meeting will take place August 19-25, following the theme: “**By Nature, Man Is Relation with the Infinite,**” and will host, as every year, shows, exhibits, and conferences. This presentation, held at the Italian Embassy to the Holy See, welcomed Cardinal Leonardo Sandri, Prefect of the Congregation for Oriental Churches; Giulio Terzi, Italian Foreign Minister; Ivan Caracalla, Director of the Caracalla Dance Theatre, hosted by Meeting President Emilia Guarnieri and Companionship of Works President Bernhard Scholz. The Rome gathering was the final one in a series of presentations held in the Netherlands, Russia, Lebanon, and Serbia, a tour that demonstrates the internationality of the Rimini event.

The first stop was on April 29th, in ‘s-Hertogenbosch, the Netherlands. Here, the presence of CL has been historically linked to the Meeting. Speakers at the gathering were Fr. Ubaldo Orlandelli, a Missionary of Saint Charles Borromeo, and Dutch Cardinal Adrianus Simonis. The presentation was one of a series of cultural evenings that the CL community proposed in that city, beginning in November.

Next, it was Russia’s turn. At the Pokrovskije Vorota Cultural Center in Moscow, Jean-François Thiry, Director of the Library of the Spirit, and Tat’jana Kasatkina, who will participate

in this year’s Meeting with an exhibit on Dostoyevsky, along with Fr. Georgij Orechanov, Vice Rector for International Relations at the San Tichon Orthodox University of Moscow, spoke about the upcoming Meeting. Fr. Georgij, who, through his work at the Library of the Spirit, came into contact with the experience of CL, said that what struck him most about the Rimini manifestation was its being “something authentic” in a world in which homogenization reigns and where imitation seems to be the dominant characteristic of every sphere of knowledge.



The presentation in Russia (Moscow).



The presentation in Lebanon.

Then, **at the end of May, the Meeting organizers flew for the first time to Lebanon.** At the Italian Embassy, introduced by Ambassador Antonio Morabito, there were contributions by Ivan Caracalla; Mohammed Sammak, General Secretary for the National

Committee of Islamic-Christian Dialogue; and Ibrahim Shamseddine, founder of the Imam Shamseddine Foundation for Dialogue of Beirut, himself a guest at the next Meeting.

Finally, in Serbia, thanks to the friendship that arose last year with the Branko Orthodox Children’s Choir, the Meeting was presented on June 3rd during the Nis and Bisanzio Conference in the conference hall of the University of Nis. On June 4th, there was also a public meeting in Belgrade with Bishop Stanislav Hocevar.

To learn more about the Meeting program see: www.meetingrimini.org.



» would have left them there until the little one died.

Instead, he lived twelve hours, and spent them with his parents and young siblings. It was beautiful to see how they celebrated him...”

This opportunity, which previously was extemporaneous, has for four years had the name of neonatal hospice, but it was never anything planned. “I didn’t do anything. Every step of mine was prepared by an Other,” Elvira recounts. She arrived in New York at the suggestion of Fr. Giusani: “Why don’t you go to America?” It was 1986, when she was 30 years old, and she did not know a word of English. She began with a year’s research, then a few times back and forth, and finally returned for good in 1994. In line for the interview at New York University, along with scores of candidates in dark suits, she was wearing a flowery dress. “There I understood that I had no idea what I was doing.” But she followed. Seven years later, she became assistant professor at Columbia University, where she had started out at point zero, as an intern.

In the midst of all the changes, one thing always remained the same: “The desire to care for sick or malformed newborns. I become very fond of them.” Why? “Because they are needy. And then because they are given to me.” In 2001, she started work with the team of perinatologists at Columbia, where all the specialists, from the geneticist to the surgeon, examine the high-risk pregnancies. “The default proposal was abortion, without discussion. They did not even have me speak with the mothers. And every time, it was an incredible suffering, but I didn’t want to be indignant and battle them, because it would have been useless. In the end, I was so saddened that I left.” After three years of absence, one morning

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Above, the Morgan Stanley Children's Hospital of Columbia University; Right, Elvira with two interns, and the neonatal intensive care.

the head of Obstetrics, who was pro-abortion, met her on the ward. “Elvira, why don’t you come to the meetings any more? You learn so many things there. Come on, return!” Just this, a quick exchange in the corridor. “I didn’t hesitate a second. I said, ‘You want me there, Lord. I’ll return. I’ll suffer, but at least I’ll suffer with those children who will not even be allowed to be born.’”

At the first meeting she attended, among the cases being examined were those of two women expecting children with Trisomy 18 and, strikingly, “they didn’t want to abort. So then I said, ‘Give me these mothers; I’ll follow them. When the children are born, we’ll provide them with comfort care.’ But I didn’t even know well what I was saying.” She only knew she wanted “the life of those two children to be wonderful, and for those women to have a chance to be mothers to the very end.” This was in 2006. From that day, obstetri-

cians and secretaries began sending her all the mothers who decided to keep their babies, those in doubt, and those who could not abort because the diagnosis came after the 23rd week. Everything began this way. There was never anyone who said, ‘Now let’s set up a neonatal hospice.’ The hospice was born between the lines and operates this way.

GLAD IN THE MIDST OF TEARAS. Elvira’s team also evolved along the way. “Today there are almost ten of us, including nurses from Obstetrics and Neonatology, a gynecologist and a social worker. Almost all of these sought me out first, asking to work with us.” The strongest reason for this committed interest, and least articulated, is for those moments in which beauty happens: “You can’t explain beauty, but your heart recognizes it, intercepts it.” The parents are the first to do so. “I continue to do what I do because I can’t remember one case—in the last four years we have followed 56 cases—in which the mother and father were not grateful, glad in the



midst of their tears. They tell me, ‘You helped us to be parents.’ And these people are very diverse; this is rarely a ‘moral’ or ‘religious’ choice. Instead, it is the response to a desire written in the heart.”

The uniqueness of the Columbia hospice is its “medical” idea of comfort care. In other hospitals, the common mentality is: “I know that the baby will die, so I’ll stop intensive care.” But this can mean everything, even stopping nutrition, to the point of becoming a shortcut to euthanasia. The borderline is dizzying. Similarly, one can err and slide into the opposite, that of unnecessarily prolonging artificial life support, keeping the baby alive at all costs because you can’t stand seeing him die. But this way, he dies in pieces. The road to take is discovered only through experience. “The only road is reality. Reality speaks. The baby gives us all the signs we need, because he is given, to the parents and to me, to us, who cannot define his destiny. Only the One who gave it knows where it goes. We are asked to observe and follow reality.”

There have been newborns in comfort care who did not die, in contrast to the prognosis. Alejandra was born premature with a grave infection that destroyed her intestines. The surgeons decided that the only thing to do was wait for her to expire. “We started comfort care, we kept her two months, with the minimum of nutrition and morphine every two hours! In everything, you have to ask yourself if you are exceeding the limit. With Alejandra, we decided to keep her in life support with minimal settings, because she was a premature infant and ‘healthy.’ Premature babies may need this kind of support until they can breathe on their own. The fact is that at a certain point, she began breathing on her own, and improving.” Today Alejandra is 4 years old, and her mother Sandra says that she has been cared for “every day as if it were her last.” It is striking to hear Elvira say, point blank, “I have nev-

er erred.” Not because she always got the treatment right; rather, she does not even believe that there is a “right choice” or a “wrong one.” “It is an entirely different thing to follow reality. It is a dialogue with the Mystery who makes it. But all our life is like this: it develops either in a way that you lead, and you live in total anguish, or one in which you respond. Since Christ was made flesh, reality reveals Him, and you don’t have to invent anything.” You put all your energy into that dialogue, and you risk following, because the evidence with which reality speaks to you is not peaceful. “For me, it’s always very dramatic. It engages my freedom, mine and that of the parent. However, it asks only one thing of me: purity in looking at the situation.”

THE RISK AND THE HINT. Thus, life and work are a prayer in action, continually praying for a hint. Elvira is a member of the *Memores Domini*. “My work is the greatest verification of my vocation,” she says. “Vocation is following the fact that Jesus is everything of my life. Here, I see His victory over ugliness, over evil, and

over death.” She is frank in speaking of the Mystery: “It is not beautiful not to live. And those children do not live, or live very little. I don’t know why, but I see the Cross of Jesus and the Resurrection.” She touches them, while they are present, as when she bap-

tized the little Siamese twins before they died. They were there on the bed, embraced with each other and identical. She began to make the sign of the cross on the first: “I baptize you Keela...” The boy-father grasped her arm: “No! She’s Kayla...” The gaze of that father on his daughters was that of God. “Only He loves us this way. One by one.”

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