

# Prenatal diagnosis of a lethal defect: What next? History of first family in perinatal hospice

Aleksandra Korzeniewska-Eksterowicz, M.D., PH.D.<sup>1,2</sup> , Joanna Kozinska<sup>3</sup>,  
Konrad Kozinski<sup>3</sup> and Urszula Dryja, M.D.<sup>2</sup>

## Essay/Personal Reflection

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### Author for correspondence:

Aleksandra Korzeniewska-Eksterowicz,  
Pediatric Palliative Care Unit,  
Department of Pediatrics, Oncology and  
Hematology, Medical University of Lodz,  
36/50 Sporna Str., 91-738 Lodz, Poland.  
E-mail: [aleksandra.korzeniewska-eksterowicz@umed.lodz.pl](mailto:aleksandra.korzeniewska-eksterowicz@umed.lodz.pl)

<sup>1</sup>Pediatric Palliative Care Unit, Department of Pediatrics, Oncology and Hematology, Medical University of Lodz, Lodz, Poland; <sup>2</sup>Gajusz Foundation, Pediatric Palliative Care Center, Lodz, Poland and <sup>3</sup>Parents in Gajusz Foundation, Pediatric Palliative Care Center, Lodz, Poland

This is a story about Mieszko, a special boy — our first patient in perinatal hospice (PH). The story is told from the doctors' and parents' perspectives. At the beginning of PH activity, our principles and priorities were entirely new for hospitals in our region (Korzeniewska-Eksterowicz et al., 2013a, 2013b). The most difficult to change was how the family is perceived by hospital personnel, that they were aware that in a situation of such loss medical issues become less important. From Mieszko's death, 8 years elapsed. Expectations, which were controversial at first, have become standard care now (American Academy of Pediatrics, 2019; Wool and Catlin, 2019). Mieszko fought for his parents and at the same time showed us doctors that we need to fight and change the “medical world.”

### PH pediatricians' perspective

The parents contacted PH in 29 weeks of pregnancy. They knew that their son will die, and only did not know when (in 16-week multiple systems) malformations and abnormal karyotype were revealed. The aim of our team was to prepare the parents for their son's death. During first meeting in PH, the child's disease was discussed, and information about the lack of possibility of causative treatment was confirmed. The most important fact for the parents was possibility to say goodbye to the child. We were all well prepared theoretically, knew which standards of care we were aiming for and would expect from the hospital team. However, we were not prepared for brutal reality. The first call from PH to hospital asking for a meeting with the head of department was met with surprise. This first meeting was difficult, from our perspective we asked for obvious things, but from the hospital perspective, these were things way beyond normal procedures. We asked for isolation of the mother from other women expecting the birth of healthy children, for the presence of the father during delivery, and for the possibility of contact between the mother and child after delivery in a separate room. The biggest controversy was raised by a request of photography performed by a professional photographer. For us it was obvious that it would be the only way of “freezing” the few moments with the child, that something more than just a gravestone would be left, short parenthood documented, and that it will be important for the family in the future, should other children appear. For the hospital personnel, it was shocking, and they felt that it is cruel to document death. Our arguments based on research gradually changed their view and we received permission (Meredith, 2000; Institute of Medical Illustrators, 2006). Further meetings were with the parents who stated what was important for them and although hospital team were still skeptical, there were no more negative emotions. The delivery was planned via cesarean section and our hospice pediatricians and priest were present. Mieszko was immediately baptized. The boy was placed in a separated room, where the father and other members of the family could be present, as well as the hospice doctor and photographer. Mieszko was taken to his mother to the obstetric department in an incubator. Minimal therapy was introduced and the boy died within 23 h in the presence of both parents. The plan was conducted in 100%. Eventually, the hospital team thanked HP team for their presence.

### Mother's perspective

I had a beautiful dream, a dream that lasted 40 weeks and 4 days. My dream, my love, my darling son gave me a special gift, he gave me hope that miracles can happen, that love can conquer anything, that people are good.

Before I got pregnant with Mieszko I had two miscarriages, we did all possible tests, we were healthy. However, our tiny 159 g son was not ... The verdict was possible lethal defect. The diagnosis was confirmed by two doctors. Pregnancy termination was suggested. I did not agree. I prayed that it was not true. I was waiting for the amniocentesis result for a month. I remember precisely, 30th May, Friday, 1 pm, we were waiting for the courier in

the outpatients office. I was called to the room and got my results. Nobody said a word, I was just handed a yellow page and “do what you want.” For a long time, I was reading again and again complex medical statement, how? why? Finally, I realized what it meant — my son’s karyotype was abnormal — monosomy of chromosome 13: 90% of such fetuses die within first 3 months of pregnancy, only about 0.4% live long enough to be born. Despite merciless diagnosis, I savored every day of carrying this tiny being under my heart, every move I felt. This was the most important. This is what I want to remember.

I decided that no matter what, I am going to enjoy this pregnancy and live through it as every pregnant woman. And I really celebrated this time. I wanted to use it best as with every minute I was getting closer to delivery, and it could mean death for my son. My husband chose the name for our son: Mieszko. This name has always been special for me, meant strength, persistence. And so, stubbornly we both thrived, Mieszko and I.

I prayed for Mieszko to be born alive. I wanted our grandparents and siblings to see him, to be able to baptize him, meet us, and feel the love we had for him. For me there is nothing worse than not to be able to say goodbye. I went through this twice. I could not see my babies, say goodbye, I never knew what happened to them.

Cesarean section was planned for 25th September. Mieszko was born at 8.50, I barely remember it, with all the emotions and anesthesia. My husband was present in the operating theater. For a short while I saw the doctor holding a small red being, there was silence and for a moment which was eternity for me I could not hear him breathing or crying. And then, I heard a very soft wailing. I saw Mieszko. My husband told me that he was baptized. I was transported to the postoperative room.

I was scared, paralyzed with fear. What now? I am here, far from my baby. When will I see him? I wanted to get up and run, control what he was going through. My son was no longer in me, he was now on his own. Please, God, make him strong as you made me. I must see him. Finally, the door opened and an incubator was rolled in. A midwife placed Mieszko by my side. A tiny dwarf, in a far too big hat, socks reaching above his knees, so tiny, wrapped in a flannel cloth with yellow giraffes print (Figure 1). I could barely hold him. I suddenly felt so tired and all bad feelings disappeared. You are here. You are alive. This is me, your mother. I love you son, be brave. Now daddy will take care of you, but when I feel stronger I will meet you again. I barely remember anything due to emotions, if there was no photographer, I would have nothing to hold on to.

I was in postoperative ward. My husband sent text messages — he was fine, he was stable. I was thinking: I will wake up tomorrow, wash, go to Mieszko, and watch over him all day. However, I did not have this opportunity. When I was woken up in the morning, I knew why. But I managed to say goodbye.

Thank you God for this miracle. Mieszko was with me. I met him, he met me. My family met him, he was baptized. Godparents held him. Grandparents caressed him. I kissed him goodbye. I am proud that I had such a son.

### Father’s perspective

Until recently, I thought that my life can be divided into several chapters — childhood, school, studies, and work. Now I see that the only demarcation is the birth of my son Mieszko and



Fig. 1. Family in postoperative room.

his short one-day time with us. Thinking about my life I tend to think now “this was before Mieszko.” The time started again after his death.

After initial diagnosis we felt cheated, disappointed, as if somebody promised us something and then went back on the promise. My wife did not give up. I could not resist then but slowly got used to the thought that our child has a lethal defect. We decided to pick a name for him. We wrote a few suggestions and Mieszko was the only one we both wanted.

Thanks to PH, we managed to achieve everything important for us. Several weeks before delivery, we met with the head of neonatology, in the presence of a doctor from the hospice. We came to an agreement as to my presence in the delivery theater, the presence of a priest who was to baptize Mieszko after birth.

I thank God that he let us to see him, to baptize Mieszko, and say goodbye to him.

This one day — when he was with us — became the most wonderful day in all my life.

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