

# THE PLAIN DEALER

Hope and reality

**Parents forced to make life-and-death decisions need solid advice so they can do their best for their children**

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Readers who followed Plain Dealer reporter Diana Keough's recent series, "At What Cost?", which chronicled the treatment of two local girls with juvenile Tay-Sachs disease, had the advantage of dispassionately weighing the ethical, medical and emotional arguments for and against the radical treatment the parents chose.

That kind of detachment is a luxury the parents of Dakota Bihn and Alexis Markowich never had. They were emotionally consumed, as any parent would be, by the drive to do the best they could for their little girls.

Anyone who has never faced the necessity of making life-and-death decisions about a son or daughter cannot even begin to know what these families have gone through. Nor can anyone spared those awful choices sit in fair judgment of those families' decisions.

Knowing that, especially in the short term, the cure might well be worse than the disease, Ken and Julie Bihn and Craig and Nichole Markowich sorted through their options and decided that they weren't going to let their daughters die without a fight.

And the only fight on offer was the battle plan of Dr. Joanne Kurtzberg, a research hematologist at Duke University, who told both families that a transplant of umbilical cord blood might slow or even reverse the effects of Tay-Sachs.

Other doctors Keough interviewed said Kurtzberg oversold the likelihood that the treatment would be beneficial.

Kurtzberg calls her approach the standard of care for juvenile Tay-Sachs, a phrase that a reasonable person would probably use to describe a recognized treatment with a recognizable history of success. But her colleagues argue that the track record just isn't there - that only in Kurtzberg's view is cord blood transplantation for Tay-Sachs the standard of care.

After a long and painful treatment, Alexis died. Dakota still lives, but it is impossible to say for sure whether the transplant has done anything to arrest the progress of Tay-Sachs.

The human stories of both families are compelling, but the underlying story of medical ethics - the question of whether a doctor is offering hope rooted in fact rather than hope founded only on more hope - is the one that demands the public's full attention.

There is truth in Kurtzberg's contention that if doctors never tested new approaches, the progress of medical science would grind forward more slowly. But it's hard to escape the sense that her cord blood transplants for Tay-Sachs have been shots in the dark.

The ethicists interviewed for the articles presented a far stronger argument: Parents want to hope, and physicians must be extra careful not to offer them false hope.

"The parents can't be trusted . . . because they are so desperate to do some good," said University of Pennsylvania bioethicist Arthur Caplan.

Ultimately, though, parents must be trusted with a great deal of latitude, because they are primarily responsible for whatever happens to their children.

What parents facing awful choices need is expert information from many quarters. A second medical opinion isn't enough. Nor can "informed consent" amount to simply skimming and signing a legal document filled with medical jargon. Hospitals doing advanced research involving people of any age should make it a practice for patients or their guardians to meet with ethicists, clergy and as many physicians as it takes to clarify the risks, the likely outcomes and the possible unintended consequences of a procedure, as well as less aggressive alternatives. Sometimes the most attractive alternative will be to let nature take its cruel course.

Sometimes even a shot in the dark hits the mark, and we join the Bihns in hoping that Dakota will recover to the greatest extent possible.

We cannot, however, conclude that Kurtzberg exercised the best medical or ethical judgment in any of the Tay-Sachs cases she took on. The administration at Duke should undertake a full review of her work.