My Toughest Case

Diagnosing an Unnamed Disease

As a pediatric pathologist and Medical Director of Laboratories at Louisiana State University, Dr. Randall Craver's entire practice is based around taking care of children.

"Giving information is most of what I do," says Craver. "I don't treat, but I provide doctors the diagnosis for them to treat children, or information for the doctors and the families for how to make plans to deal with the child's illness."

Working as a pediatric pathologist is not for the faint of heart – Craver has to deal with the deaths of children on a daily basis. Despite the seemingly grim job description, he loves his line of work.

"So much of the disease in adults is self-inflicted from bad habits, but the children didn't do it to themselves. When a child becomes ill, everybody in the family is involved with their care, from the parents to the grandparents. You want them to get well. That's what you expect - for them to grow up."

Craver explains that when a child is sick, the concern also extends to the child's siblings if the disease has a genetic component. There is always the matter of how the child's illness might affect the brothers and sisters, as well as the possibility that it could affect subsequent pregnancies.

Part of Craver's job as a pediatric pathologist includes looking at the deaths of newborns or stillborns in order to provide information as to what lead to the baby's death, either in utero or soon after birth.

Craver brings up a specific instance of a case where the mother-to-be had a viral infection that was transferred to the baby in utero. The virus didn't manifest in the baby until a day or two after birth and the baby didn't handle it as well as the mother.

"Cases like that are hard because you're dealing with a perfectly normal baby all of a sudden dying," says Craver. "Where I come in is [telling the family] - this is the information, it's this type of virus, the likelihood that this is going to reoccur in the next pregnancy is very little."

"Those are hard - meeting with the parents to discuss the death of a child and trying to give them information at a time when they're still mourning to make plans for the future pregnancy. There's a lot of denial, there's a lot of wanting somebody to blame, and people that don't know me think I'm defending the doctors ... and that's a natural concern. But I'm trying to give them and the doctors information so that during the next pregnancy, the chance of success is better."

Craver considers this particular case a success story. Although the first baby didn't survive, the mother became pregnant again two years later and the doctors knew what to watch out for. The mother was able to deliver a healthy baby.

Craver says that one of his hardest cases occurred several years ago when he was working with a world-famous orthopedic surgeon who was preparing to amputate the leg of a child. After the operation, he ran tests on the amputated leg, but it didn't fit any typical disease process that he or the other doctors could classify. "All the soft tissues were turning into bone – hard bone. We didn't have a good name for it."

After working with another researcher in Pennsylvania who collected a few other similar cases, the doctors coined a new term: Progressive Heterotopic Ossification.

Craver explains that rare and unusual diseases that are sometimes completely unheard of in the medical world cannot simply be diagnosed together under one common name. "If you lump them together, they can have different causes. Part of what our job is, is to separate these out - collect them - so that when we study them, genetically, they may make more sense."