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Testimony in favor of HB 482 "Donor-conceived Persons and Families of Donor-conceived Persons Protection Act"

As an adult who discovered rather late in my life that I was donor conceived, I strongly support the proposed bill to assist people "in my boat" in gaining access to vital family medical information.

I was born in Grand Rapids, Michigan in 1958. I went through the first 55 years of my life assuming I was the biological child of both my mom and my dad. I was extremely lucky – although I had been given misleading information to all my doctors for all those years, I'm still in good health.

The risks, however, in having erroneous or even incomplete family medical histories, can be fatal.

In my case, both my mom's family and my dad's family were vulnerable to cardio-vascular disease and not much else. In particular, no one on either side had had any cancer of any kind. Consequently, none of my doctors were particularly worried that I might be at higher risk than usual for any of the cancers that have a known genetic influence, such as breast cancer or colon cancer. So I followed the usual schedule for a mammogram and a colonoscopy, starting at age 50.

At age 55, after both my parents had passed away, and having taken a genetic test with 23andme, I learned the truth: that my Dad was not my biological father, and that my parents availed themselves of a sperm donor for my conception. This was an emotional shock, but the more important question on my mind was whether I should be worried about anything other than cardio-vascular disease.

It took me five years and the help of genetic-genealogy "search angels" but we succeeded in identifying two donor-conceived half-siblings and our biological father, who had been a medical student and resident at the University of Michigan hospital in the late 1950s. He had passed away the previous year but we were able to contact his two children, who were kind enough to compile and share their family medical history. It turns out my biological father had died of brain cancer and his mother had died of colon cancer, both long after the time of donation. When I shared that information with my own doctor, he said I should have been on the "early and often" scheduled for colonoscopy, and I should be on the "often" schedule starting immediately. Although my first colonoscopy (undertaken at age 50 before I knew my correct family medical history) had been entirely "negative", the one I took at age 60 found and removed some polyps that were biopsied and found to be "potentially pre-cancerous." My next colonoscopy will be later this year.

As you're probably aware, colon cancer, in addition to being heritable, can also be deadly. I lost a colleague and friend to colon cancer several years ago who was younger than I was.

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I am lucky that I was so curious as to do a genetic test. I am lucky that I was able to identify my biological father. I am lucky his children were willing to share their family medical history with me, and to agree to keep updating each other.

This should not require luck.

I understand the desire of sperm donors to enjoy their privacy after the relevant transaction. I understand the desire of commercial fertility clinics to avoid any new regulations or bureaucratic requirements. I understand the desire of people who want to conceive a child and want the maximum choice of gametes.

I know that legislators have to balance the competing interests of a wide variety of stakeholders.

I want you to know that the rights of people like me, who are donor conceived, at the moment, are near zero. Our interests have been ignored or disregarded for decades. Those of us testifying on this bill understand there can be no legal remedy, ever, for our situation.

Going forward, we are asking you to prioritize a donor-conceived person's rights for family medical information, which can have life-or-death stakes, for the next generation. That is the very least that any person deserves.

I urge a favorable report for HB 482.

Thank you.

Jacqueline Coolidge

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