

Living with hemophilia: When patients with genetic disorders don't want to be cured

Jeff Johnson is 40 years old, and for all 40 of those years, he has been living with hemophilia. The genetic disorder prevents blood from properly clotting, which, if untreated, can cause uncontrollable bleeding. Yet, Johnson says, he does not want a cure. He grew up with hemophilia, went to summer camp with kids with hemophilia, and forged some of his closest relationships within the community.

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In two conversations, we spoke about his experience growing up with hemophilia, his sense of identity, and his hopes for his newborn baby girl. The interview has been lightly edited and condensed for clarity.

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Zhang: You've been talking about some of the challenges of living with hemophilia. So why are you personally not interested in a cure?

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[Johnson:] I am hemophilia. I don't have it. I am hemophilia. So when they come to me and say, "We've got a genetic cure for hemophilia," to me, that's just as weird as if you said you've got a genetic cure on the horizon for your left foot. This is really who I am.

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Zhang: Did you think about the possibility of passing hemophilia to your kids?

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I'm educated, I work in the community, I would feel confident handling my daughter's hemophilia. It doesn't bother me. Whether she does or she doesn't, I know we can have a full, thriving life with hemophilia.

Read full, original post: [The Patients Who Don't Want to Be Cured](#)