I was incidentally diagnosed with Alport syndrome based on routine labs prior to a knee operation in 1996 at the age of 20, and very shortly thereafter started hemodialysis. In 1997, I received a kidney transplant, but I unfortunately experienced acute rejection and returned to hemodialysis. With high antibody titers, I was very pessimistic about my chances of ever getting a new kidney graft.

Without the opportunity to get a transplant, I learned to live with dialysis. At the beginning, I endured it with difficulty, since for more than 5 years I had to organize my weeks according to its constraints.

I worked full time, attending in-center hemodialysis sessions thrice weekly from 6:30 PM to 10:30 PM. It meant very busy days, both physically and mentally demanding. A vicious cycle developed in which illness took up a lot of space, especially in my free time: very little spare time, no more physical activity, and a diminished investment in my work.

Nocturnal hemodialysis changed my vision of the disease and of my own potential.

In 2002, my doctor told me about a new opportunity to try nocturnal dialysis. While it had its own constraints—leaving my family 3 nights a week can be emotionally demanding, and getting a full night of restorative sleep takes a bit of practice—it saved me a huge amount of time and helped me keep my full-time job. The difference compared to short dialysis sessions was also remarkable: improvements in blood pressure and phospho-calcium balance despite fewer medications, better tolerance of hemodialysis sessions, and disappearance of posttreatment asthenia. The benefits for my quality of life were undeniable.

Having always been a sportsman, I was able to consider training again. It was a nurse at the hemodialysis center who first shared with me her passion for running. I started with a 10-kilometer run, and within a year I was able to tackle my first marathon. In 2006, during the famous Paris Marathon, there was an advertisement for the even more famous “Grand Raid de la Réunion.” This competition features the “Madmen’s Diagonal,” a mountain ultramarathon race that takes place annually in Island of Réunion, a French overseas département in the Indian Ocean near Madagascar. I had always been passionate about mountains and the great outdoors, so I was immediately captivated.

In 2017, I registered for the “Trail de Bourbon,” an ancillary race to the Madmen’s Diagonal that covers 112 kilometers and 6,500 meters of altitude gain. I was just one competitor among others, and I had only 44 hours between hemodialysis sessions to complete it. I wanted to create a documentary to raise awareness among dialysis facilities and health care workers of the way that nocturnal dialysis had enabled me to take on this challenge. In the end, we created a 55-minute film, called “The Mountain in His Blood” (teaser available at https://vimeo.com/473319130). The aim of this documentary is to share with other patients and their relatives a story of desires, adventures, and passion—feelings that may be lacking initially when starting dialysis. For me, the start of nocturnal hemodialysis was life changing, however every patient has a different perspective on disease. Whatever technique is used, there is always a way to combine travel, interests, and enjoyment with the disease—and I hope this movie will help many patients pursue their own passions.

Fabrice Huré
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Fabrice Huré is a 44-year-old patient who has undergone hemodialysis since 1997. Despite his restrictive treatment Fabrice has managed to remain active in his professional life (in the past 24 years he has never stopped working) and he is still passionate about mountains and extreme sports.

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