

Bulletin de la Dialyse à Domicile

A testimony about home dialysis in Tougué (Guinea) using the NxStage® portable haemodialysis system

(Un témoignage concernant la dialyse à domicile à Tougué à l'aide de la machine portable d'hémodialyse NxStage®)

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Résumé

Plusieurs témoignages sont déjà parus dans le Bulletin de la Dialyse à Domicile ou le site du Registre de Dialyse péritonéale de Langue Française pour évoquer des expériences patients remarquables par leur autonomisation au domicile (1), ou bien par la réalisation de défis sportifs et humains comme celui de Fabrice HURÉ (2) ou de Jean Louis CLEMENDOT (3). Le témoignage que nous rapportons est le récit de voyage de Mr Alhassane DIALLO, patient dialysé qui a voulu rejoindre sa famille en Guinée à grande distance de toute structure de dialyse, un voyage que la dialyse à domicile a permise mais non sans épreuves. Nous espérons que cette expérience puisse venir en aide à d'autres patients ayant un projet de voyage en autonomie. La réussite de ce projet a tenu à la détermination sans faille de Mr DIALLO mais aussi à une organisation collective qui a sollicité les services administratifs, logistiques et pharmacie de la fondation AUB Santé et la coopération étroite entre les équipes médicales française et guinéenne. Cette expérience nous montre combien les limitations de déplacement sont importantes dans l'expérience des patients dialysés singulièrement dans celle des patients expatriés. Par ailleurs, elle rappelle les inégalités importantes d'accès aux soins dans le monde puisque la Guinée ne dispose que d'un seul centre de dialyse à Conakry.

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*L'AUB Santé est un établissement de santé intervenant dans les domaines de la prévention et du traitement de la maladie rénale chronique. Elle est devenue une fondation d'utilité publique en 2017.

Mots clés : hemodialyse, voyage, Guinée, expatrié, dialyse à domicile, NxStage, hémodialyse portable.

Summary

Several testimonials have already appeared in the Bulletin de la Dialyse à Domicile or the website of the French-language Peritoneal Dialysis Registry detailing patient experiences remarkable for their empowerment at home (1), or for the achievement of sports and human challenges such as that of Fabrice HURE (2) or Jean Louis CLEMENDOT (3). The testimony we report is the travel story of Mr Alhassane DIALLO, a dialysis patient who wanted to join his family in Guinea at a great distance from any dialysis clinic, a journey that home dialysis allowed, but not without hardships. We hope that this experience can help other patients with independent travel plans. The success of this project was due to the unwavering determination of Mr DIALLO but also to a collective organization that requested the administrative, logistical and pharmacy services of the AUB Santé Foundation and close cooperation between the French and Guinean medical teams. This experience shows us how important travel limitations are in the experience of dialysis patients, and particularly in that of expatriate patients. In addition, it highlights the significant inequalities in access to care in the world: Guinea has only one dialysis centre, in Conakry.

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*AUB Santé is a health care institution involved in the prevention and treatment of chronic kidney disease. It became a public benefit foundation in 2017.

Key words: hemodialysis, travel, expatriate, home-dialysis, NxStage, portable haemodialysis system.

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INTRODUCTION

I am 33 years old, I am of Guinean nationality and I have been dialyzed since 19 December 2011. That is, I have undergone over 10 years of dialysis. I am married without children.

My testimony is the story of a trip to my family in my hometown Tougué, which is located in Guinea, 500 km from the capital, Conakry. This trip would not have been possible if I had not been able to perform my dialysis autonomously on the NxStage® machine.

History of my illness

I started dialysis on 19 December 2011 in Malaysia, where I had been awarded a scholarship to do my master's. My kidney failure was diagnosed at a very advanced stage. I started my dialysis sessions right away, and at the same time, I continued my master's studies in telecommunications. After graduation, it was impossible for me to return to Guinea due to my health situation. I sought admission to a master's program in order to quickly enter the professional world as a telecom engineer. I obtained admission to a major university in France and a study visa for my stay.

When I arrived in Rennes in September 2015, the AUB Santé Foundation offered to do night-time dialysis for me. I must admit that this was very much appreciated, because it meant I had all my days free.

There was a big change following the switch from daytime dialysis (4 hours) to night-long dialysis (8 hours). Although I still feel some fatigue after night-time dialysis, it is much less than what I felt after daytime dialysis. I had pain in both my feet that completely disappeared with night dialysis. Over time, I also stopped taking my blood pressure medication, which is a positive thing. The only negative point I found about night dialysis is that I had to take phosphorus because I was deficient in phosphorus just 3 months after starting night-time dialysis. But this is tolerable considering the benefits of night dialysis (possibility to work during the day, less medication, no pain in the feet...). In Rennes, I was registered on the transplant list, but with a temporary contraindication (CIT), because I had a bone defect on my left hip as well as the Hepatitis B virus. After these two issues were resolved, my CIT was lifted in December 2019. I received a transplant on 4 January 2020, but unfortunately the transplant was not successful due to a thrombosis of the graft vein. The graft was removed in less than 24 hours. A great hope was lost because I developed a lot of anti-HLA antibodies 3 months after the transplant. To this day, these antibodies have not disappeared, and no solution has been proposed to me.

Because of this failure of the transplant and the conditions of the health system in Guinea, it seemed impossible to see my family and my relatives because my birthplace (Tougué) is 500 km from the capital, Conakry, where the only dialysis centre in Guinea is located, and the journey is long and difficult.

In February 2021, I was sad to lose my dear father in Tougué. Because of this death, I made the decision to return to my family in May 2021.

Decision to go to Tougué

The AUB Santé Foundation, which focuses on home dialysis, offered to train me on the use of the NxStage® machine. The training was mainly focused on the following:

- Knowing how to correctly set up the machine and manage the alarms independently
- Mastering self-puncture with the required hygiene

The main difficulty was to provide in Guinea the 5-litre bags of dialysate, which are used with the machine at a rate of 40 litres per dialysis session. During my training, AUB and I continued to look for a way to deliver these bags to Guinea. The AUB pharmacy told me that it was important to follow hygiene and 'temperature maintenance standards' for the bags during shipping and in Guinea. The required temperature is between 15 and 30 degrees. The plan was to store the bags at a satisfactory temperature conditions in a pharmacy in Guinea before my departure for Tougué. During the Conakry-Tougué trip, it was possible to ensure transport in the best conditions in an air-conditioned car. Once in Tougué, the bags would be stored in the air-conditioned health centre. It remained to send the bags.

I contacted a friend in Senegal who visited all the big pharmacies but could not find any. I considered sending them by sea. I asked on a WhatsApp® group of Guinean friends if they knew of anyone who could arrange for the transport of materials to Guinea by boat. I quickly got an answer and the contact information of a person who does this once a month via the port of Havre. I also asked the dialysis centre in Conakry how the dialysis material was delivered. The centre put me in touch with the director of the SOGUIMAP company (Mrs. RACH). This very benevolent person offered to have the bags transported free of charge. In the meantime, the AUB Santé pharmacy had also contacted the forwarding agent of this company, which is based in Rouen. In short, we were able to transport two pallets of dialysate: one by boat from Le Havre and the other via Mrs RACH. AUB Santé decided on this arrangement this for security reasons. The bags arrived in Guinea at the same time.

Purchase of the ticket for the NxStage machine

This step was a bit laborious with Air France because it was the first time such a request had been made. I first contacted the SAPHIR service (an assistance service for people with disabilities for information and reservations) of Air France to explain that I wanted to travel with the dialysis machine. I was told that there were two options: either to carry it in the hold or to buy a ticket in the cabin for the machine. But the first option was not possible because checked luggage is limited to 23 kg. So I took the option to buy the ticket for the machine.

Transport of the machine: Sunday 28 March, 2021

I had also asked SAPHIR for assistance in pushing the machine through the airport, but they informed me that I was not entitled to assistance in airports to push the machine or to board the plane because I am not in a wheelchair. Air France does not have a baggage assistance service. I found this strange because I have an 80% disability card issued by the MDPH (department for disabled persons). Considering that the machine weighs 35 kg, it is not easy to walk with it in the airport in the time allotted for a connection, but fortunately I managed well.

So the day of the flight, I took the machine with my two suitcases, one of which contained the smaller pieces of dialysis equipment (needles, set of bandages, box of haemostatic bandages, bottle of alcohol, pair of gloves, big roll of scotch tape, syringes, masks, hydroalcoholic gel ...) and the equipment that goes with the cyclor (heater, integrated foot). Dr LARUELLE had issued me two medical certificates (one for the machine and the second for the small equipment) that described the equipment I carried.

When I got off the plane at Roissy, I had to push the machine from hall F to hall E where we boarded for Guinea. This long journey was not easy, but fortunately I had about 2 hours of stop-over. When I arrived at the boarding gate, I showed the boarding pass of the machine and I boarded after having answered the multiple questions the staff had because they were not aware of the machine. As it was a long-haul flight, the machine could not be placed on the business seats. So they placed the machine in the small cabin at the entrance of the plane. I finally went on to my two seats because the machine did not occupy its seat from Paris to Conakry, which was also the case on the return trip (Conakry to Paris).

Arrival in Conakry

Once in Conakry, and after I had gone through the police formalities, I called the porters to accompany me to the airport exit, where my brother was waiting. Customs delayed us despite the presentation of the medical certificate.

First day of dialysis : Monday March 29, 2021

The day after my arrival in Conakry, I had to do a first dialysis at the Gbessia Dialysis Centre in Conakry. Unfortunately, I could not do the first dialysis as planned because of a thrombosis of the fistula. When I came to the centre, I pricked myself, but I could not see any blood in the needle. The nephrologist, Dr CHERIF, also listened to the fistula, but it was already blocked. We decided to do a quick ultrasound, and it showed extensive thrombosis along the fistula. This was quite surprising to me because I had done an angioplasty two days before flying. Following the discovery of this thrombosis, I was told that there was no solution on site to perform an angioplasty. The only solution was to put in a catheter to dialyze, which I had to do the next day.

Announcement of the bad news to my mother who was waiting for me in Tougué

I had a hard time telling my mom and my wife the bad news. They cried because it was such a surprise. My wife cried because she knew how moved I was by this stay in Tougué. It is difficult to describe everything. As for my mother, she cried because for her, I could no longer go to Tougué, but I managed to explain to her that I was planning to return to France to solve the problem of the fistula, and to leave during the end of widowhood ceremony. This was an extremely difficult time for her. Given the lack of transportation infrastructure in Guinea (flight or train), she could not consider coming to Conakry so quickly because of the state of the road.

Return to France

On Thursday, 31 March, I came to the airport in Conakry to return to France. When I arrived in Rennes, I went directly to the University Hospital to be taken care of. I had the chance to be taken

care of quickly, and fortunately my fistula was repaired.

Plan to return to Guinea

I had decided to return to Guinea in June 2021 in order to attend the end of widowhood ceremony of my mother in Tougué. However, in agreement with Dr LARUELLE, I chose to wait a few more months to make sure that my fistula would not pose a new problem (the bags of dialysate transported to and stored in Conakry expired on 15 May 2022). I concluded that given the difficulty of lifting the machine, I would go with Air France cargo for my next trip with the NxStage®. I would not advise someone who cannot easily lift the machine to travel alone with it by plane unless the person obtains an escort agreement beforehand.

Decision to return to Guinea

In November 2021, I decided to plan a return to Guinea even though I had no real explanation for the cause of the fistula thrombosis. The hypothesis that had been put forward by the doctors was that it could have been related to the high-altitude pressure in the flight. In agreement with my doctor, I resumed dialysis via NxStage® once a week until early February 2022. This allowed me to have more autonomy because I normally do not dialyze at home.

Purchase of the new ticket for the NxStage machine

When I contacted Air France cargo, they told me that they didn't transport equipment for individuals. So I went back to Air France again to get an additional ticket for the machine.

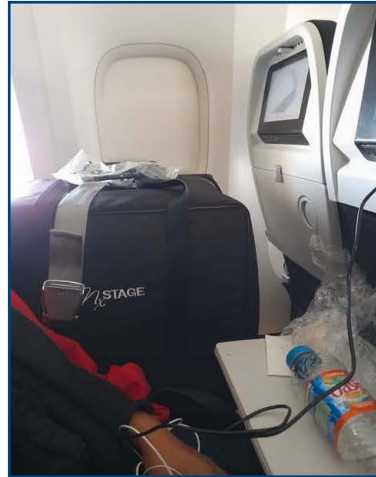
This time, I asked the SAPHIR service to buy the ticket. I did not have any difficulty on this end because it was the second time. The only constraint I had was that I was obliged to embark either in Nantes (as during the first trip) or in Paris because the flight that leaves Rennes is a small one that cannot transport the NxStage® in the cabin given its dimensions.

Transport of the machine: Friday 4 February 2022

The day of the flight, I went very early to Nantes with my wife, who was travelling with me this time. As on the first trip, we had difficulties getting the machine through the scanner, despite all my explanations. The team manager told me he could not let the machine pass because their scanner did not detect what was inside. After several discussions, they decided to send the machine to another station where they scan the oversized luggage and where the diplomatic corps passes through. Once there, they do a scanning technique called TDM (explosive detection technique) to be sure of what is inside the machine. Once this operation was done, they accompanied me to take the machine. It was very frustrating because I had all the documents signed by the AUB doctor and it was the second time I had gone through this process with this machine. Anyway, I figured this was all because they didn't know the dialysis business. I would advise any patient who wants to travel with this machine to be thoroughly prepared and know how to explain what the machine does in order to minimise the time lost. Once we were on the plane, a friend of mine who was also going to Conakry helped us to put the machine in its seat and we strapped it in like on the first flight.

Course of the flight

The flight from Paris to Conakry has a duration of 6 hours. We installed the NxStage® in its own seat, as shown in this picture:



After 4 hours of flight, I felt a little fistula-related pain due to swelling at the level of the first centimetres, as shown in this picture.



Fortunately, there was a very good thrill and I was able to finish the flight without the fistula becoming blocked. So the hypothesis that had been put forward concerning the pressure in the plane seemed to be confirmed.

Arrival in Conakry

This time, the customs officials at the airport in Conakry did not ask anything about the machine. When I arrived home, I called the nephrologist in Guinea to describe the condition of my fistula. He advised me to take coumadin and to come see him the next day.

First day of dialysis : Saturday, 5 February 2022

Very early in the morning, I went to the SOGUIMAP Company, which had stocked the dialysis equipment, to get what I needed for the first session.

Once I was at the dialysis centre, the nephrologist checked the fistula and confirmed that I could dialyze because the thrill was there. That was the first good news. I then set up the NxStage® machine under the observation of several people because it was the first time that we had used this machine in Guinea. Among the people present, there was a nephrologist who had done his training in Paris, and so he was the only one who knew the machine. He even asked me if I had not brought the tablet to enter the data from the dialysis session. As I mainly practise night dialysis, I did not have a tablet. After the installation of the machine and the boot phase (23 minutes), I made all the necessary connections and then I finished by entering the data (weight to be lost, dialysate volume, etc). At each step, I had to explain to the staff who were present the purpose of each manipulation. It was as if I was the trainer in a way. The picture below shows the first session:

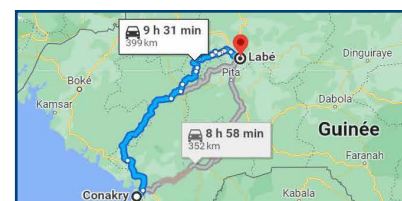


First dialysis session with NxStage® in the dialysis center of Gbessia in Conakry

In total, I did three sessions in this dialysis centre before leaving for my parents' home in Tougué.

Trip to Tougué on Thursday, February 10, 2022

To go to Tougué, I rented an air-conditioned 4X4 driven by a driver who knew the road well. We loaded all the material and we attached the machine to a seat at the back because there are several km of the road without bitumen. We left Conakry on 10 February at 7:30 am and we arrived in Labé at 10 pm. We spent the night in Labé. I want to specify that we avoided driving very fast because I was too afraid to damage the machine with shocks related to the bad road. The following photo illustrates the journey:



The next day, we continued on to Tougué, and we made a little more than 3 hours of progress. I would like to point out that the Labé-Tougué road has never been paved, even during the French colonisation. The route and the Labé-Tougué track are presented below:





Labé –Tougué trail

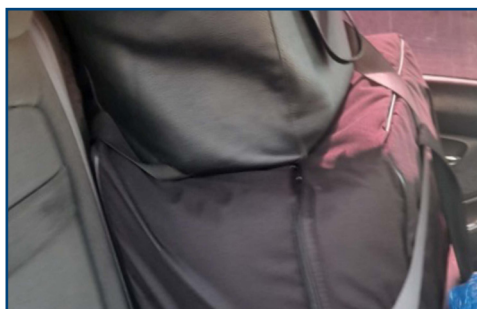
These pictures show the equipment and the machine in its suitcase:



Dialysis equipment transported to Tougué



NxStage® machine transported to Tougué in its suitcase

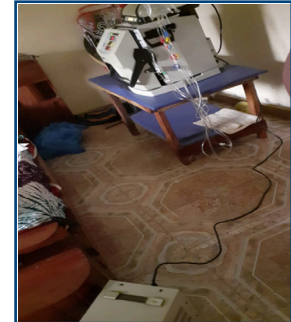


NxStage® attached with belt in the car

Dialysis in Tougué

In Tougué, we went to the health centre where I had chosen to dialyze, but unfortunately, the staff informed me that there was only one room, and that this room was reserved for the observation of patients. I then contacted the prefectural hospital of Tougué, but there too I was informed that they were receiving cases of COVID-19 and that they did not want me to be exposed, since I was a person at risk. These explanations were quite understandable. So I talked with my family and we decided to do the sessions at home. I would like to point out that I had chosen to go to a health care facility so that I would not be exposed to too much with my family, and that I was afraid of the negative comments from people who were not familiar with dialysis.

The prefecture of Tougué is one of the last prefectures of Guinea in terms of infrastructure. There is no electricity in Tougué, and I planned to do my dialysis session with a generator. I had brought a stabiliser to know the voltage of the NxStage® to avoid damaging it. The electrical connection was as follows: the generator fed the stabiliser, and the stabiliser fed the NxStage® as shown in these pictures:



First session with the generator in Tougué



End of the session

End of the session

At the end of the session, we noticed that it was dark in the room because there was no electricity. I used the lighted torch in addition to the light from the telephone. However, despite these conditions I was very happy because I was able to accomplish my goal.

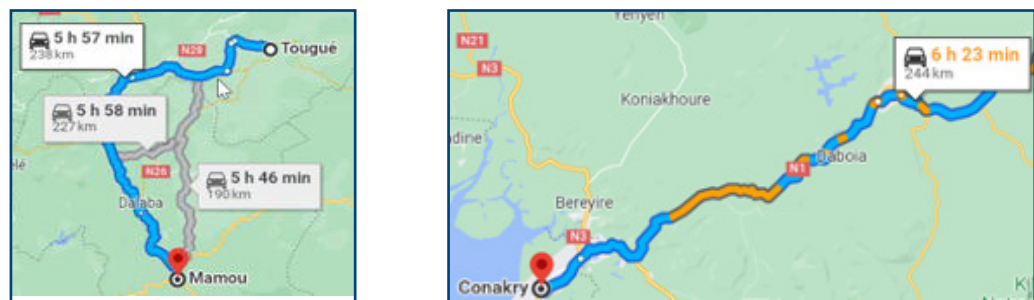
After the success of this first session, I was completely liberated in my head because I understood that I could stay one week in Tougué.

In total, I had three dialysis sessions in Tougué, and I must admit that I was able to meet several

relatives who I had missed for several years. The greatest relief was due to the fact that I was able to pray in place for my late father. Then, my family understood what dialysis is, and they demystified this disease, which is unknown to the general public.

Return to Conakry on Thursday 18 February 2022

After having carried out three sessions in Tougué with this generator, I took leave of my relatives to return to Conakry. The return also lasted two days because of the state of the road. Moreover, I had other people to meet in certain cities like Labé. We spent the night in Mamou before continuing on to Conakry on Friday, 19 February, as this route illustrates:



Dialysis at my brother's home in Conakry on Saturday, 20 February, 2022

When I arrived in Conakry on Friday evening, I asked my brother if I could have a session at his place instead of going to the dialysis centre, which is very far from our house. Moreover, there are many traffic jams in Conakry. My brother even encouraged me to do this session at home because he understood that I was perfectly autonomous with the machine. The only risk we took was that of an electric fault because there is regular load-shedding in Conakry. EDG (Electricity of Guinea) is not reliable for a 4-hour session at home because a power cut can come at any time. Fortunately, I was able to do a complete session that day without a power outage. The following picture shows the session done at my brother's house:



Return to France on Monday 21 February 2022

Arriving at the airport in Conakry, I asked for assistance to help me to deposit the machine on its seat. Fortunately, the airport staff accepted and everything went well in Conakry.

As on the outbound trip, I was worried about the return trip because of my fistula. I contacted the Air France doctor in Conakry to see if he could give me some advice on how to avoid clogging the fistula during the flight. During the entire flight, I monitored the fistula thrill and when I ar-

rived in Paris, I noticed that the fistula was working well, even though there was some swelling on the arm where the fistula is located.

The flight staff took the machine down and the assistance worked this time because the assistant agreed to put the machine on a wheelchair. He accompanied me well until the boarding to Nantes.

CONCLUSION

Successfully travelling with the NxStage® was extremely liberating for me. It allowed me to return to Tougué to stay for a week with my loved ones and pray for my late father. It was also an opportunity for my relatives to discover and demystify dialysis. I am completely liberated in my mind and I am very satisfied to have done self-dialysis in my hometown. From now on, I can always resort to this kind of trip if I am not lucky enough to get a transplant.

ACKNOWLEDGEMENTS

I give infinite thanks to Dr LARUELLE; my nurse trainer for dialysis, Yann Gael SALAUN; Mr Philippe ROLLAND, director of AUB Santé; Mr PICOT from the logistics service and Mrs DOLLO, pharmacist at AUB Santé; the night nurses; my wife; Mrs RACH of SOGUIMAP; Pr KABA; Dr CHERIF and the staff of the dialysis centre in Conakry; and any other person who supported me and contributed in any way to the execution of this project.

CONFLICT OF INTEREST

The authors declare no conflict of interest other than being dialysed with the NxStage® hemodialysis machine

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