

## Exploring home: A patient experience with domestic travel

Antonis Chatzisavvas, Patient Advocate & Eirini Kotsifakou, Care partner



# INTRODUCTION

#### Antonis Hadjisavvas DIALYSIS PATIENT FOR 40 YEARS

Former President of the Panhellenic Renal Patient Association, President of Renal Patients Athletics Association (SAN), founder of DIALYSIS LIVING renal journal, <u>nephron.gr</u> - a news portal website for kidney disease and inventor of peritoneal dialysis suitcase SMART PD CASE / Bachelor Degree in Marketing



#### Irene Kotsifakou

CAREGIVER - WIFE - BUSINESS CO-FOUNDER Married with Antonios, caregiver and co-founder of **DIALYSIS LIVING** renal journal, <u>nephron.gr</u> and **SMART PD CASE - peritoneal dialysis suitcase** / Bachelor Degree in Business Administration

#### **Antonis' life**



At age of 24 years old I was suddenly diagnosed with ESRD:

"I was in shock, I was depressed and sadness was my new mental state of mind. My future was full of obstacles and there was nothing to hope for"

## Life on dialysis

/ After the first shock and the start of dialysis therapy, I eventually felt strong. I started playing music and sports again, which I had given up. I was now in the age of acceptance and coexistence with kidney disease.

I realised that I had to stay in the workforce after initiation of dialysis. I couldn't find a job as an employee, due to the difficulties of dialysis (limited time, feeling sick sometimes, often missing from work due to health issues). So Self-employment was my only way-out !

/ I also realised the importance of education and being an active member of society. I engaged with social activism to help people on dialysis

/ Also I believed that travelling should not be a distant dream, but a certain option for dialysis patients. So I started arranging my domestic travels, exploring home while on dialysis.

In 2011 me and my wife, decided to buy a camper (RV) to explore Greece and this adventurous lifestyle became our priority!



# Problems of patients with CKD (Chronic Kidney Disease) in terms of travelling in Greece

01

- Patients with CKD face multiple problems associated with their health state. Fatigue and other symptoms of renal failure are the everyday reality for kidney patients, that become barriers for a balanced working and social active life. These barriers are limiting travelling options for ESRD patients, as they have to cope with the anxiety of changing dialysis units during travelling and the quality of medical treatment that they will receive.
  - Dialysis patients also need to arrange in advance the treatments in a centre close to the preferred destination. Some times the HD centres are busy and may limit the ability to find a dialysis centre which can accommodate dialysis patients close to where they wish to travel to. This is common in Greece during the summer months, especially August! So you have to plan ahead !

02

- Sometimes small places in the countryside don't have HD centres nearby and you have to travel for long distances until you get on dialysis. Also this may cause extra stress in case of emergency, so you have to be extra cautious in terms of food and fluids intake.
- This is also under consideration if you plan to travel in islands. Sometimes you have to narrow down the places you want to visit and limit your choices only to mainland destinations that are far easy to reach.
- Deal with the anxiety of the new nurse that will take care of you and access your fistula! Every patient has its own fears. After 40 years on dialysis, the fear of the needle is still there!
- Patients on dialysis need emotional and physical assistance sometimes, thus relying to their caregiver for support. So you should always have a partner to count on!

## LIFE ON DIALYSIS - CAMPER LIFE!

In 2011 we bough our camper (RV). Since then our life is full of travelling experiences and new places that are still there to find out!

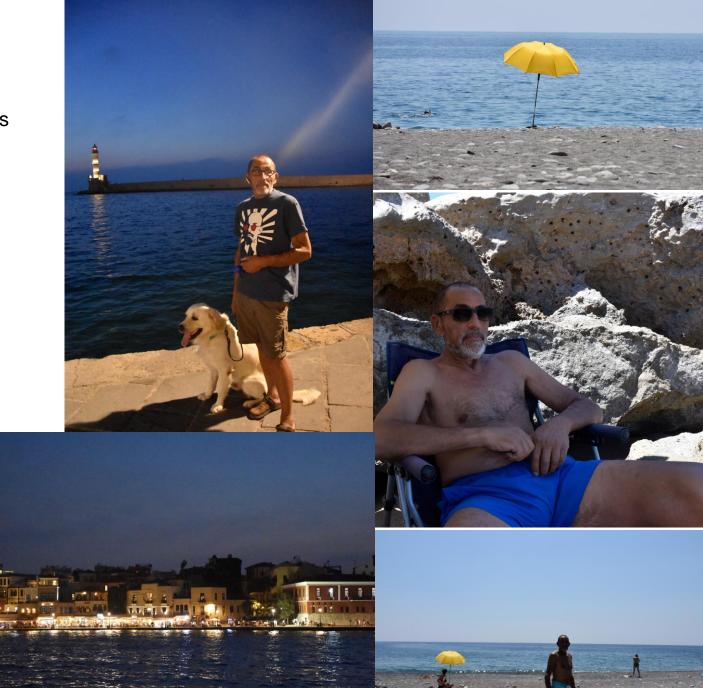


### **Dialysis destination Crete**

Crete is the biggest island in Greece. It is almost like the mainland. You can easily accommodate your dialysis sessions in high quality HD centres. Maybe during August your options will be limited, because its high tourism season for the island.

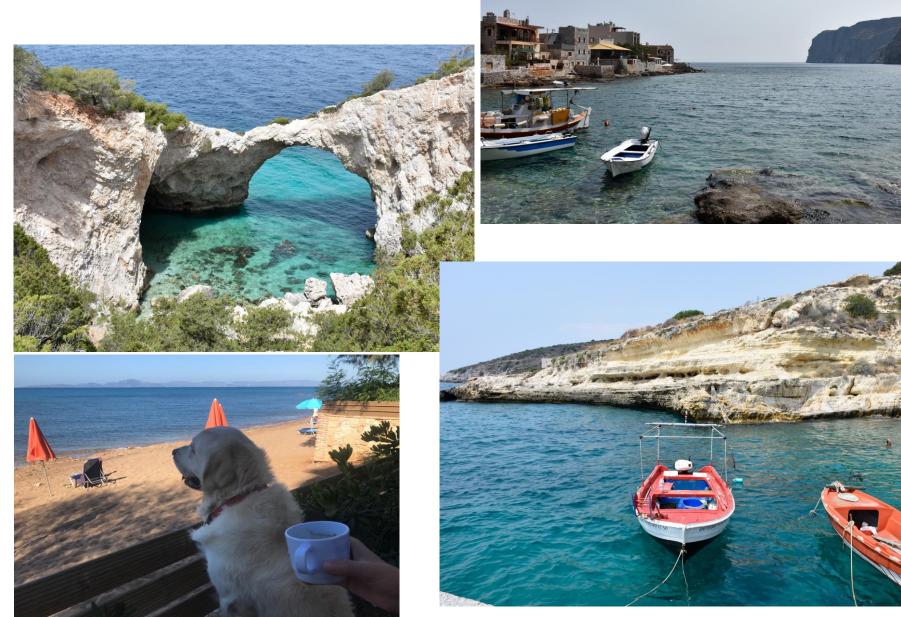






#### Dialysis destination Peloponnese

Peloponnese is the preferred vacation place for the Athenians, due to proximity and majestic places that you can find. Whatever you may like is in this part of Greece. Gorgeous mountains, magnificent rivers, breathtaking views, turquoise clear sea waters, sandy or rocky beaches, beautiful towns and picturesque villages. Just drive and you will find a place suitable for you. And dialysis is easy to arrange, in the most places of Peloponnese.



#### Dialysis destination Peloponnese

We are also choosing Peloponnese for weekends with our camper, without the need of arranging dialysis elsewhere. This is a preferred way of mini vacations during early summer, before our planned holidays.



#### Dialysis destination Mainland

We have travelled in so many places, throughout different seasons. Mainland Greece has to offer unlimited experiences and you may consider it as a hidden gem!







#### Dialysis destination Mainland

Mainland has several options for vacations. Mainland has also many mountains, gorgeous villages, shady forests, but also beautiful beaches! Some places are distant or with difficult roads through the mountains. So if you are planning your holidays in mainland Greece, choose wise and consider the roads!







# Life on peritoneal dialysis

In 2000 Antonis invented the SMART PD CASE, portable peritoneal dialysis suitcase.

While he was into peritoneal dialysis and during that time he realised that the big problem of CAPD (Continuous ambulatory peritoneal dialysis) is the **safe transportation**, **heating & storage of solutions**, even for a day. He understood, that if he wanted to move due to his work or his social needs, this was not possible since he had to carry more or less a room full of equipment.

When the idea for the suitcase came, there was no thought of actually producing such a product. It was designed initially for personal use and convenience. But as the time was going by and Antonis was moving around participating to social events, people and other patients in PD started noticing it.





He, thus, **created a suitcase that functions as a small laboratory for the safe application of peritoneal dialysis**, which contains literally everything and allows safe travels and work without having to return home every six hours for the changes.

Antonis realised that what he made to make his **life easier and maintain his activities** could help other patients to do so. And not only that; a lot of patients who are elder and have a care giver **could use this product with the help of their care giver**.

Moreover, a lot of couples could be able with this product to enjoy together with safety a lot of activities, such as travelling.

With this product **patients could be able to continue going to their work and having a job** since they could be away from home at least for 24hrs without the need to get back to it and do the replacement therapy. This helped the psychology as well.





With this product patients could be able to continue going to their work and having a job since they could be away from home at least for 24hrs without the need to get back to it and do the replacement therapy. This helped the psychology as well.

Equity of the patients was the initial target. Not all patients could afford the product by buying it privately. Therefore, it is provided free of charge to peritoneal patients who need it, through the National Health Care System (EOPYY).

It is also approved by the National Organisation for Medicines (EOF) for CE marking, in accordance with EU legislation and it is manufactured according to ISO 9001:2015 standards.





#### IMPACT & POTENTIAL LONG-TERM BENEFITS FROM THE USE OF SMART PD CASE

#### **FREEDOM TO TRAVEL !**

- Ability for the patients to move in safety and perform the method anywhere
- Solving the problem of heating for the dialysates which is a major difficulty for the mobility of the method
- Ability for patients to maintain their social activities and life
- Ability for the patients to be able to continue work and keep or find jobs, insertion in the labor market.
- Equity provided by the fact that patients could do as much as the healthy population
- Maintaining a more "normal" way of life
- Positive impact in their psychology and their care givers
- Improvement of their well-being



#### **THANK YOU!**

