

# Diaverum d.HOLIDAY Conference

20-21 October 2021



Promoting & Encouraging  
Mobility for People with  
Kidney Disease

20th October 2021

# Patients' Mantras

*Empowerment*

*Patient-centred care*

***“PATIENTS AT THE HEART”***

***“Shared decision making”***

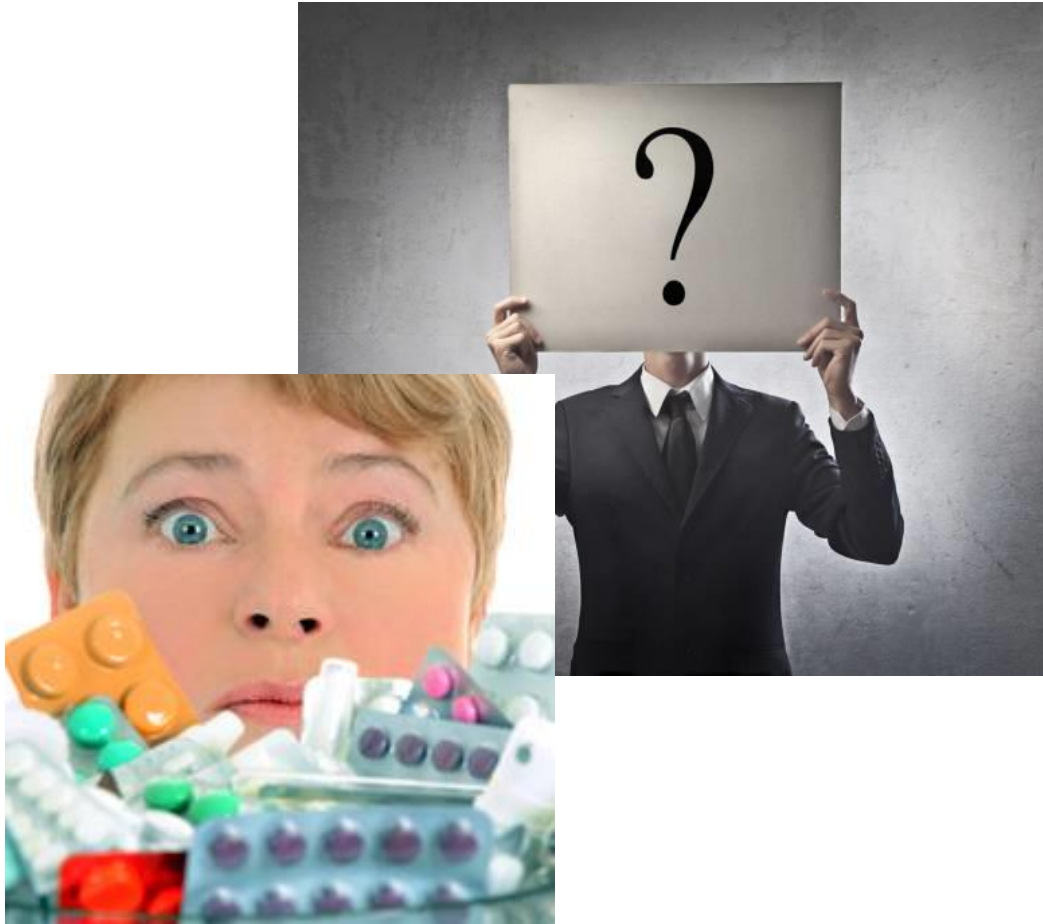
**MOBILITY**

***“Patients as drivers of innovation”***

***“Patient in the DNA of the clinical trials”***

***“Humanization of healthcare”***

# Meaning of Kidney Disease



**The person who takes medicine must recover twice, once from the disease and once from the medicine.**

- Identity Crisis
- Rejection of Appearance
- Aversion to Treatment & Medication
- Limiting Lifestyle**
- Fear and Uncertainty
- Time consumption Treatments**
- 70% Patients diagnosed with KRT believe they are going to die**



# ACTIVE LIFE & TRIPS



- ❖ *Depend on a Machine to Survive*
- ❖ *Machine is available WorldWide*
- ❖ *I LOVE HD, NO HATE IT*
- ❖ *RENAL VOAYAGER*
- ❖ *LIFE EXISTS , WITHOUT KIDNEYS !!*

# LIVING, DREAM TRAVEL



# THE DIALYSIS ❤️ JOURNEY

KYOTO,  
JAPON



CEBU,  
PHILIPPINES



NY, USA



TANGER, MOROCCO



BALI, INDONESIA



KOH SA MUI,  
THAILAND



TORONTO, CANADA



DEHRADUN,  
INDIA



# Diálisis por el mundo

□ "La gente se compra un coche, yo decidí ahorrar para viajar y pagarme la diálisis"



Daniel Gallego, en uno de sus numerosos viajes.

CRISTINA G. LUCIO > Madrid

Actualizado: 13/03/2014 05:03 horas

Para Daniel Gallego preparar un viaje no sólo supone planificar y ni encargarse de maletas, vuelos u hoteles. Este ibicenco también tiene que tener en cuenta otro detalle que la mayoría de viajeros obvian: el mapa de hospitales.

## REPORTAJE

### Viajar al extranjero en hemodiálisis

Ana Belén Martín



Roma

Está comprobado que salir a conocer nuevos lugares y culturas, que relacionarse con gente de otros países e incluso de otras ciudades o regiones tiene efectos positivos en las personas. Estar en contacto con la naturaleza, visitar museos y monumentos y en

diálisis, romper con la rutina de los mismos compañeros, enfermeras y en general con lo cotidiano ayudará a llevar su tratamiento con más optimismo, en definitiva, en diálisis se puede y se debe de viajar, pero son muchos los pacientes que tienen miedo a los

que se animan a viajar, se nota que cada vez los pacientes están más informados sobre su tratamiento y se pierde ese miedo a lo desconocido.

En el pasado Encuentro de Jóvenes en Alicante conocimos a Daniel Gallego

# «Hacerse diálisis no es una barrera a la hora de viajar»

► Un paciente valenciano con una enfermedad renal inaugura el congreso que se celebra en Valencia y que pone el foco en este tipo de patologías



Daniel Gallego, en el Palacio de Congresos de Valencia. E. RIPOLL

Gallego apuntó a las dificultades económicas que se encuentran estos enfermos dependiendo del país en el que viven

mos con las enfermeras que son las que nos dan todo lo que tienen y eso es de admirar», señaló Gallego.

**Crearé una fundación global**  
Dos millones de personas mueren al año porque no pueden permitirse el acceso a la diálisis por

# CKD FINDINGS

- Cross generational
- Found my PLACE, Giving HOPE
- Getting older appreciates much more HD
- Worst DISABILITY, Believe you wont BE ABLE

*Connected*  
**for life**

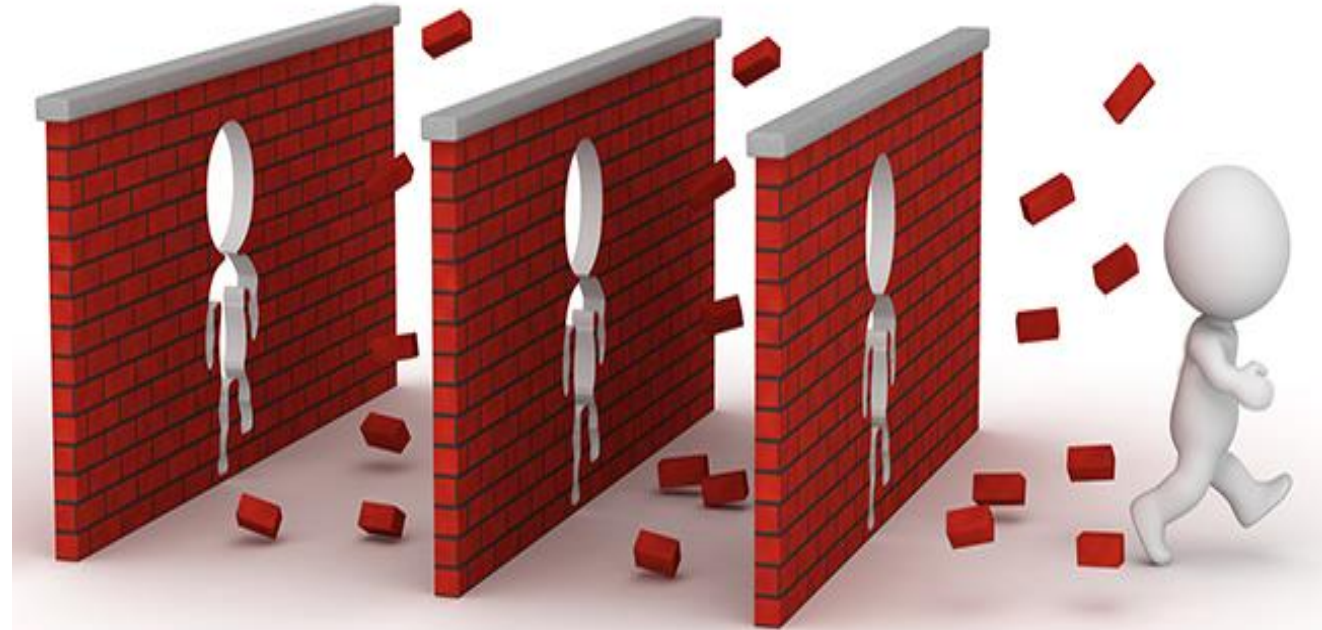


**WORKING WHILE  
ON DIALYSIS -  
IT'S POSSIBLE!**



# CKD TRAVEL BARRIERS

- Bureaucracy
- Non User-friendly forms
- Time for request
- UNCERTANTY
- Lenguage Idiom
- **Vascular Access**
- **Adherence to Medication/Treatments**



# Trip Preparation

- To know the path, walking the path
- Willing to go
- Medical report, analysis, serology, mrsa,
- Request Dialysis place (Online availability)
- Dialysis, Hospitals & itinerary
- Confirmation Dialysis place
- Sifco, European Sanitary Card (EHIC, GHIC),
- VISA / CASH

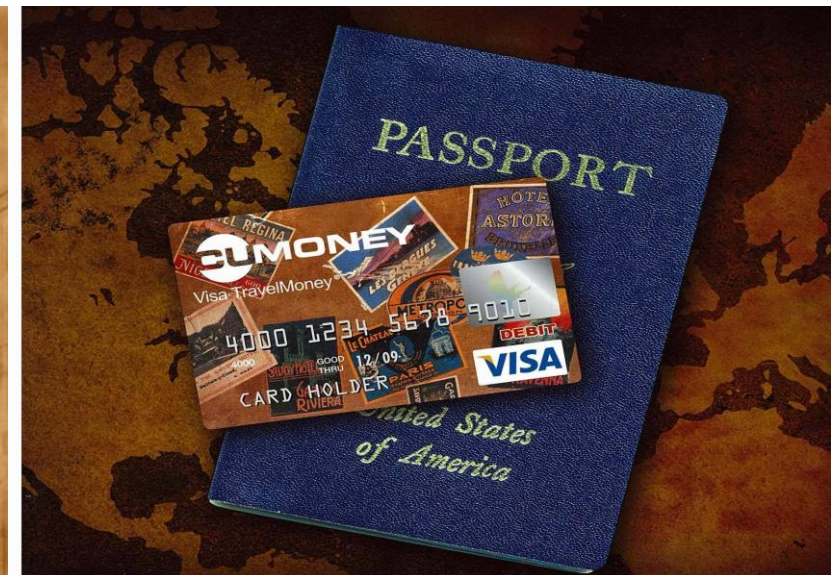


# Warranties and Safety

- Good Vascular Access
- English, Health Language
- Travel Insurance
- Map, Adresses, Phones Numbers, Emergency Call
- Medical Kit and Pill Box, Vaccines, Visas



You are free to make whatever choice you want, but you are not free from the consequences of the choice.




# TRAVEL ON THE WAITING LIST

- Transplant alarm
- PROTOCOL WITH AIRLINES/TRAVEL AGENCY
- PREFERENTIAL BOARDING
- ARRIVE WITHIN 24h
- COVER ALL RETURN EXPENSES



# BREXIT & UK SITUATION

- EHIC  GHIC
- GHIC only Works within EU
- **GHIC is not Travel Insurance**
- **Allows travel IN & OUT UK**
- **Reciprocal HC Agreement**



# EKPF MANIFESTO

- Promote Activity
- Employment
- Wedding, Job
- Holidays
- **MOBILITY is a RIGHT**

**PATIENT SAFETY**

**COVID-19**  
Kidney patients in dialysis and using immunosuppression should be regarded as a high-risk group. Many of them are elderly and have impaired kidney function and other co-morbidities that increase the risk of adverse outcome of COVID-19 infection.

**ANTIMICROBIAL RESISTANCE (AMR)**  
AMR is an increasingly serious public threat, risking the effective protection and treatment of infections. Appropriate use and abuse of anti-infectives by kidney patients requires concerted efforts by us.

**HOME THERAPIES**  
Across the world, the COVID-19 pandemic has made clear the urgency of ensuring equitable access to home dialysis so that kidney patients can stay safe at home.

**PATIENT AUTONOMY**

**UNIVERSAL ACCESS**  
Kidney Replacements Therapies (KRT) universal coverage for all kidney patients. Adequate reimbursement policies and strategic investments in KRT.

**MOBILITY**  
Facilitate mobility of people with kidney disease across Europe in any KRT, even in dialysis and/or waiting list for kidney transplant. Holiday dialysis programs should allow kidney patients free movement in and out Europe area.

**EMPLOYMENT**  
Working is profoundly important to many people who have kidney failure. It can help them to have a feeling of value to society and themselves. Facilitate access to employment in any stage of kidney disease and kidney transplant.

*Preserving  
Kidney Patients'  
Dignity*



# EMPOWERMENT

- ✓ The KEY is EDUCATION
- ✓ **NOT ONLY** Information
- ✓ **PROMOTE MOBILITY**
- ✓ SUPPORT & TOOLS
- ✓ WEBINAR, RESOURCES
- ✓ RELIABLE SOURCES TRAVEL



# BURDEN ON PATIENTS

- Click & Go
- Ask for Scan, Send, Test
- PROGRAM/PROTOCOL
- BETWEEN PROFESSIONALS
- Let us Manage Your Holiday
- Easiest **MOBILITY**

**NO ACTION  
REQUIRED**





# NEW => Innovative Home Dialysis



## **REAL PORTABLE MACHINES**

- NEW TINY DEVICES
- PROMOTING MOBILITY
- NURSES
- SUPPLIES DELIVERED AT DESTINY

# HOLIDAY DIALYSIS PACKAGE

- Dialysis Treatment
- Flights / Transportation
- Transfers
- Apartment/Hotel
- Car
- Tours / Excursions
- Restaurants/Meals



# DIGNITY

- Inherent Value
- Selfcaring & Autonomy
- Choices, Options
- Mobility, Active Life
- **PERSONAL INDEPENDENCE is a RIGHT**



# TAKE MOBILITY HOME-MESSAGES

- ✓ Mobility is a Right
- ✓ Work/Holidays
- ✓ Protocols
- ✓ No Burocracy
- ✓ In Real Time
- ✓ Patient Only Say Yes
- ✓ EU Policy HD Mobility

***KIDNEY  
DISEASE IS  
LIKE  
RIDING A  
BICYCLE!  
TO KEEP YOUR  
BALANCE  
YOU MUST  
KEEP  
MOVING.....***

Thank you for your attention.



**EKPF**



**@EKPFPatients**



**@EKPFceapir**



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