

Speaker



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**US Territory (Island)
Population: 3.2 millions
of American citizens.**

**43% of the Population
Live Under Poverty
Level est. 1,400,958**

**Geographic Area:
100 x 35 miles**

Response Plan for the Management of Dialysis Patients in Puerto Rico during Emergencies

Ensuring Continuity of Care

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Main Objective

To ensure the safety and continuity of care for dialysis patients during emergencies.

Secondary Objectives: Importance of Dialysis Care during the Emergency

Who is a kidney patient?

Needs of dialysis patients.

Social determinants of health.

Emergency situations:
Impact on the health of the kidney patient by the fear of losing treatments.

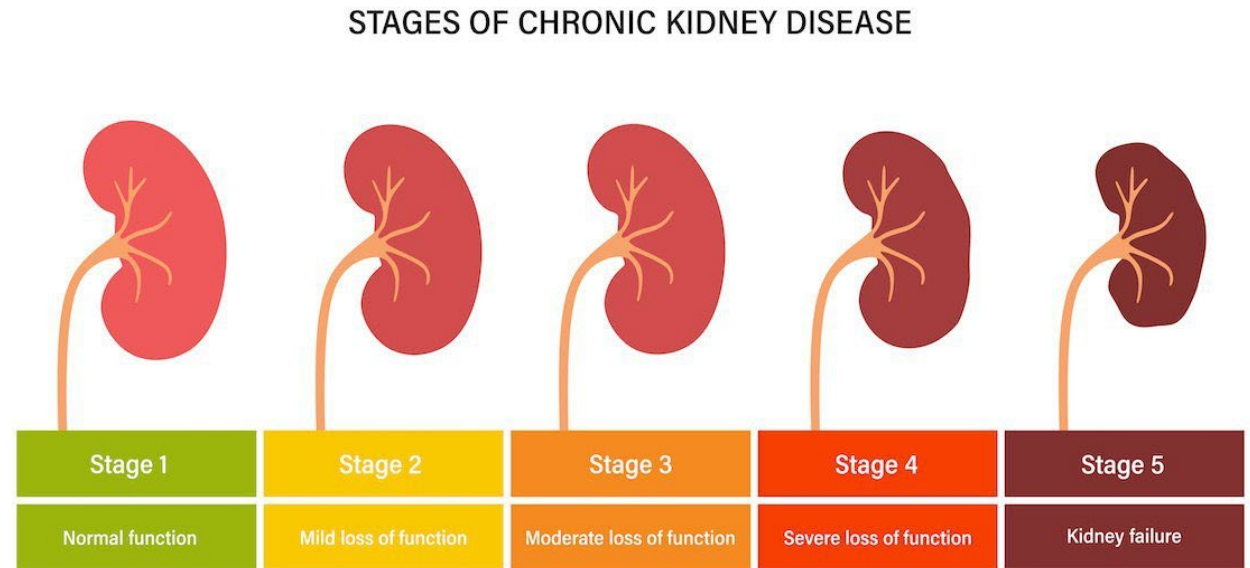
Cases.

Contingency plans.

Recommendations.

A little overview about... Chronic Kidney Disease

- The kidneys are two bean-shaped organs located on each side of the spine, just below the rib cage. Each of them is about the size of a fist.
- Its main function is to filter and remove waste, minerals and fluid from the blood through the production of urine.
- When the kidneys lose their ability to filter, unhealthy levels of fluid, electrolytes, and waste can build up in the body.



Symptoms

At the onset of chronic kidney disease, you may have no signs or symptoms. As chronic kidney disease progresses to its end stage, signs and symptoms may include the following:

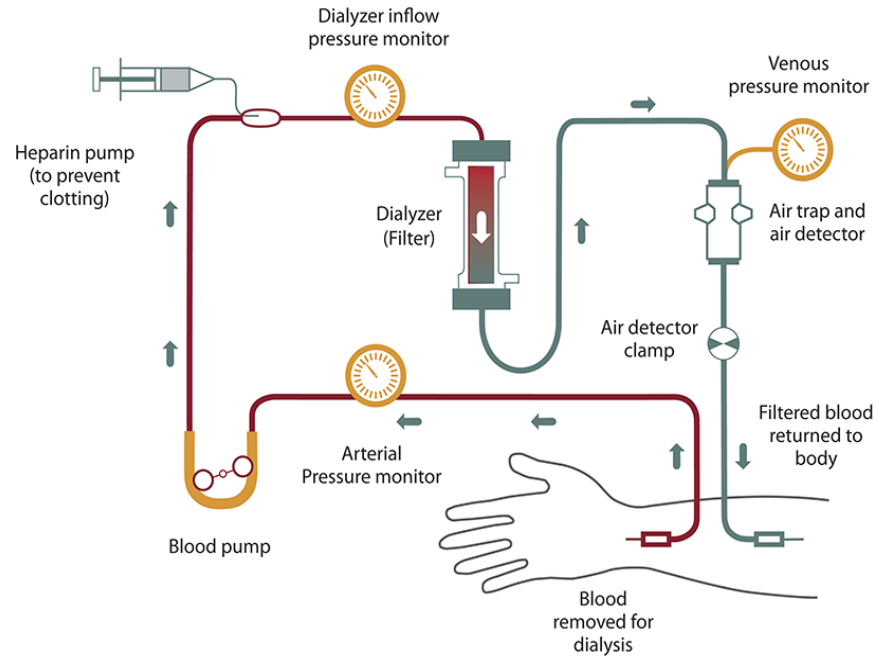
✓ Nausea	✓ Constant itching
✓ Vomiting	✓ Headaches
✓ Loss of appetite	✓ Difficulty sleeping
✓ Fatigue and weakness	✓ Decreased mental acuity
✓ Change in the amount of urine	✓ Muscle twitches and cramps
✓ Chest pain if fluid accumulates in the lining of the heart	✓ High blood pressure (hypertension) that is difficult to control
✓ Swelling of the feet and ankles	✓ Metallic taste in the mouth
✓ Shortness of breath if fluid builds up in the lungs	

Important notice:

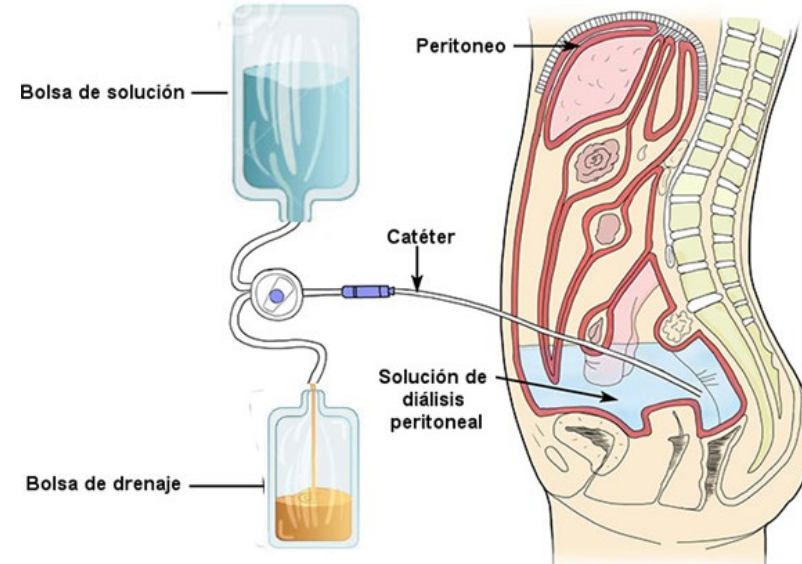
The signs and symptoms of kidney disease are often nonspecific, meaning they can also be caused by other diseases. Because your kidneys can compensate for the loss of function, signs and symptoms may appear only after irreversible damage has occurred.

Dialysis Process

Hemodialysis



Peritoneal Dialysis



Struggling with the condition

Once kidney damage occurs it cannot be reversed. Possible complications can affect almost any part of the body and may include, among others, the following:

- Fluid retention – swelling in the arms and legs, high blood pressure, or fluid in the lungs (pulmonary edema)
- Heart diseases - Low blood pressure (hypotension), high blood pressure (hypertension).
- Hyperkalemia - A sudden increase in potassium levels in the blood.
- Hyperphosphatemia – Elevated phosphorus levels. Weak bones and increased risk of fractures.
- Anemia - Problem of not having enough healthy red blood cells or hemoglobin to carry oxygen to the body's tissues
- Decreased sexual desire, erectile dysfunction or reduced fertility.
- Pregnancy complications that pose risks to the mother and developing fetus
- Damage to the central nervous system, which may cause difficulty concentrating, personality changes, or seizures.
- Lower immune response, making you more prone to infections.
- Pericarditis - inflammation of the sacular membrane that surrounds the heart (pericardium).
- Malnutrition – Deficiencies, excesses, or imbalances in a person's intake of energy and/or nutrients.

Who is a kidney patient

The person who suffers from a chronic kidney disease (CKD and chronic renal disease) means that there's damage to the kidneys and they aren't working as well as they should.

Symptoms of Chronic Kidney Disease

 <p>Dry and itchy skin.</p>	 <p>Tiredness or weakness.</p>	 <p>Bubbly or foamy pee.</p>
 <p>Swelling of hands, feet, ankles.</p>	 <p>Puffy eyes.</p>	 <p>Trouble sleeping.</p>
 <p>Loss of appetite.</p>	 <p>Muscle cramps.</p>	 <p>Need to pee more often.</p>

Kidney Patient Identification

- Target Population: Puerto Rico has a renal patient population of about 320,000 people in the early stages of the condition.
- The population of kidney patients receiving dialysis in Puerto Rico as follows: 6,590 people on dialysis and 1,700 transplant patients.
- Identifying vulnerable populations:
 - Some of the factors that can increase the risk of chronic kidney disease are diabetes, high blood pressure, heart disease, smoking and obesity. Depending on the underlying cause, some types of kidney disease can be treated.
 - Kidney disease can develop at any time, but people over the age of 60 are more likely to develop it. As people age, so do their kidneys. According to recent estimates from researchers at Johns Hopkins University, more than 50 percent of people over the age of 75 are believed to have kidney disease. It has also been found that kidney disease is more prevalent in people over the age of 60 compared to the rest of the general population. It is important to emphasize that the elderly population is part of the population at risk of an event that could become an emergency.

Dialysis patients needs

- The instability of basic needs destabilizes the most complex aspects. The lack of security in matters related to health and protection can impact the patient's mental health. Thus, affecting their adjustment/adaptation process and limiting their self-realization.
- Patients on dialysis face a number of continuous changes that affect their daily lives, routines, and family and individual environments. Including your well-being and quality of life.
- Kidney disease requires lifestyle changes. Routine tasks and activities that require physical strength may be difficult to perform now. Family or friends are a very important support resource to cope with the diagnosis.

Maslow's Hierarchy of Needs



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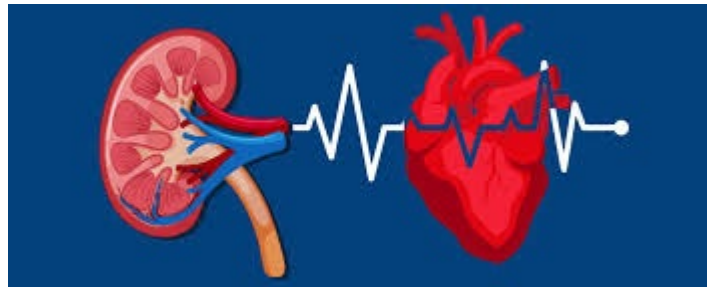
División de Preparación y
Coordinación de Respuesta
en Salud Pública

Dialysis patients have many needs, including:

- Strict Diet
- Medications
- Regular treatments
- Managing complications



- Managing other health problems
- Checking for heart disease
- Treating dry skin and itching



Social Determinants of Health in Kidney Patients

The social determinants of health are factors such as income, schooling, employment, housing, transportation, and access to health services, healthy food, clean air and water. In the case of kidney patients in Puerto Rico, poor infrastructure and data transparency are factors that contribute to the burden of chronic and terminal kidney disease.



Importance of Dialysis Care: Patient Background Profiles

Dialysis patient profile

Loss of Independence

Neuro developmental conditions

Education / Employment

Mental and physical health aspects

Limited financial resources

Social aspects

Disability / frustration

Dialysis patient family profile

Rural housing

Limited financial resources

Limited acces to transportation

Geographical area

Low academic level of the caregiver

Health conditions



Treatment Options

In-Center Hemodialysis

Home Hemodialysis

Peritoneal Dialysis (At-Home)

Kidney Transplant

Patient refuse treatment

Psychosocial Challenges for the Kidney Patient

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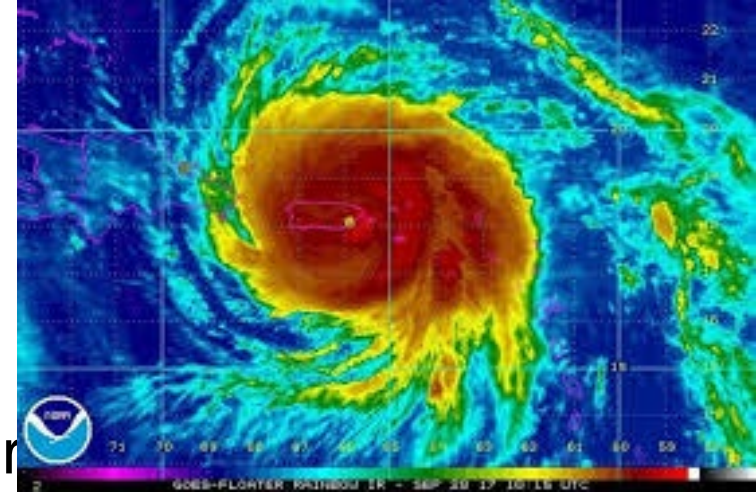
Psychosocial Challenges



Emergency Situations

Hurricane María (September 20th, 2017).

- 150 mph winds.
- Widespread damages (including dialysis treatment center)
- Destroyed the electric grid.
- Rainfall of 15 to 20 inches brought flooding across of the Island.
- Interruption of the water and sanitation services for approximately 50% of the residents.



PD. 7 years after María, utility services remain unreliable in rural areas.



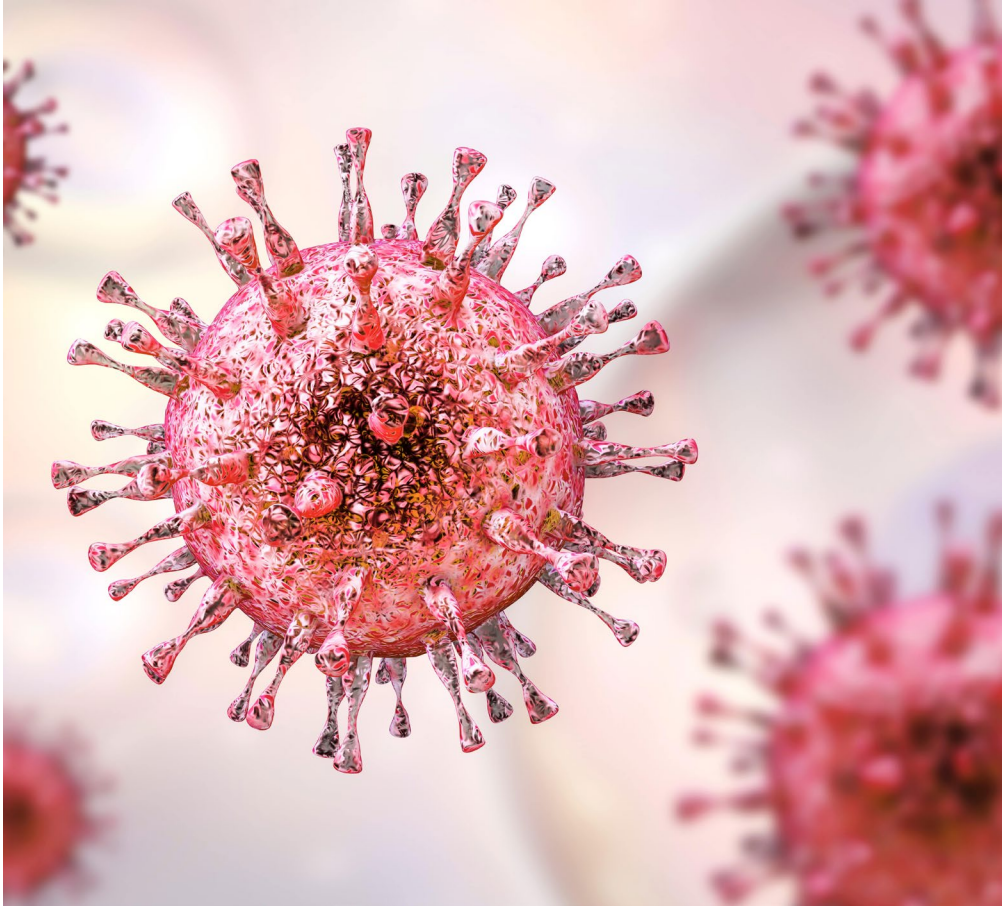
Earthquake in Puerto Rico (January 7th, 2020)

- Earthquake in Puerto Rico (January 7th, 2020) can have a significant impact on kidney patients, including:

- Disrupted care.
- Missed dialysis sessions.
- Increased hospitalizations.
- Mental health effects.
- Delayed diagnosis.



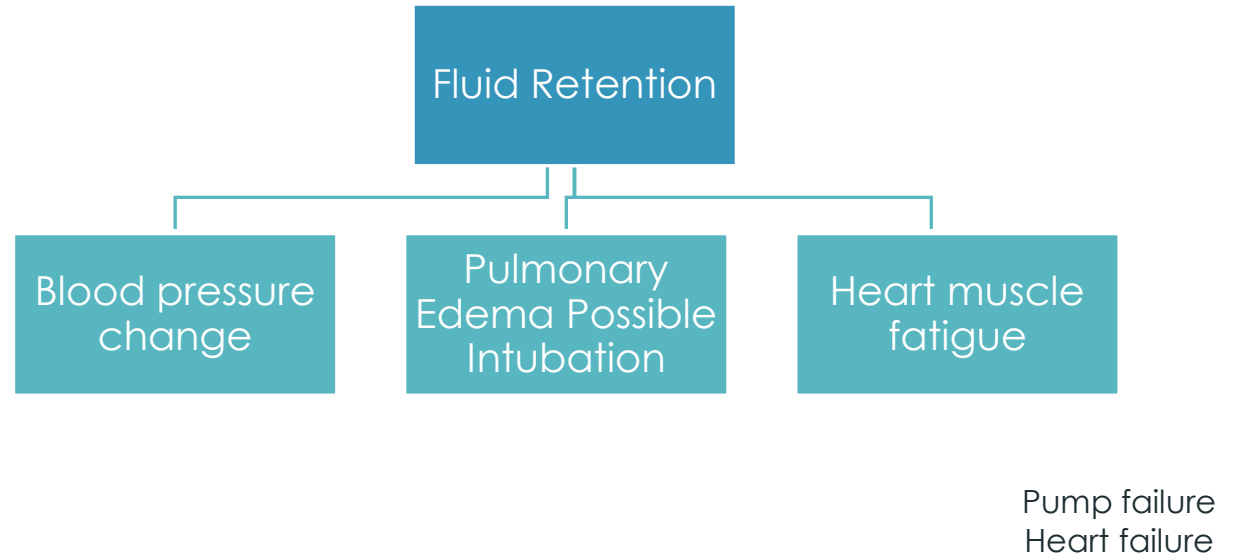
COVID-19 Pandemic (2019)



- One of the biggest challenge in the dialysis clinics, was caring for patients on dialysis during the COVID-19 pandemic. Patients on dialysis were amongst those at highest risk of death, not just because of the propensity for serious illness but also because of missed treatments.

Patient Health Impact of Losing Treatments: the biggest fear in dialysis patients

Patient non-compliance with the recommended regimen is a major problem because it affects the patient's medical condition, exacerbates patient mental health conditions such as cognitive changes, constructional praxis, altered processing level, and adds to the financial burden. A United States study reports that failure to comply with medical therapy responsibly results in 125,000 deaths each year, as well as hundreds of thousands of hospitalizations. Non-compliance with treatment in the permanent kidney disease population is a problem with significant consequences in terms of morbidity and early mortality.



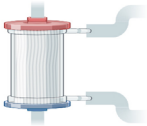
HOSPITAL

- *Reduced immune response, making you more prone to infections.*
- *Damage to the central nervous system, which may result in difficulty concentrating, personality changes or seizures.*

Communication Plan

- Communication Strategies
- Alert systems for patients.
- Coordination with local health authorities and dialysis centers.
- Use of social media and SMS for updates.

Resource Allocation



Home dialysis 4 weeks supplies



Peritoneal dialysis supplies



Medical history



Dialysis prescription

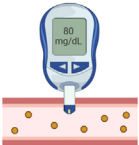
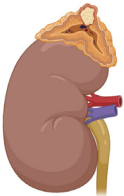
Dialysis Patient Emergency Supplies in Crisis



Dialysis Hotline Emergency contact



Evacuation Map



Glucometer



Medication List
Potassium Binders
Diuretics



Blood Pressure Cuff

- Essential Supplies
- Stockpiling dialysis supplies (dialyzers, fluids, etc.)
- Backup generators for clinics.

Communication plan during emergency

- A communication plan for dialysis patients during an emergency should include:
 - Contact information
 - Communication methods
 - Information sharing
 - Patient information
 - Facility needs



PREPARAR-C

How does it come about?

The Puerto Rico Emergency Preparedness and Response Activities Renal Coalition PREPARAR-C brings together representatives from organizations and companies that provide dialysis services to the renal population.

After the Hurricane Maria event in Puerto Rico, the companies that manage dialysis centers and the Puerto Rico Department of Health joined forces to develop an emergency management plan focused on preparedness and response activities for the dialysis population. This will ensure the continuity of dialysis services in Puerto Rico.

In emergencies that have arisen to date, the PREPARAR-C component has put into practice the response plan for the management of dialysis patients in Puerto Rico during emergencies.

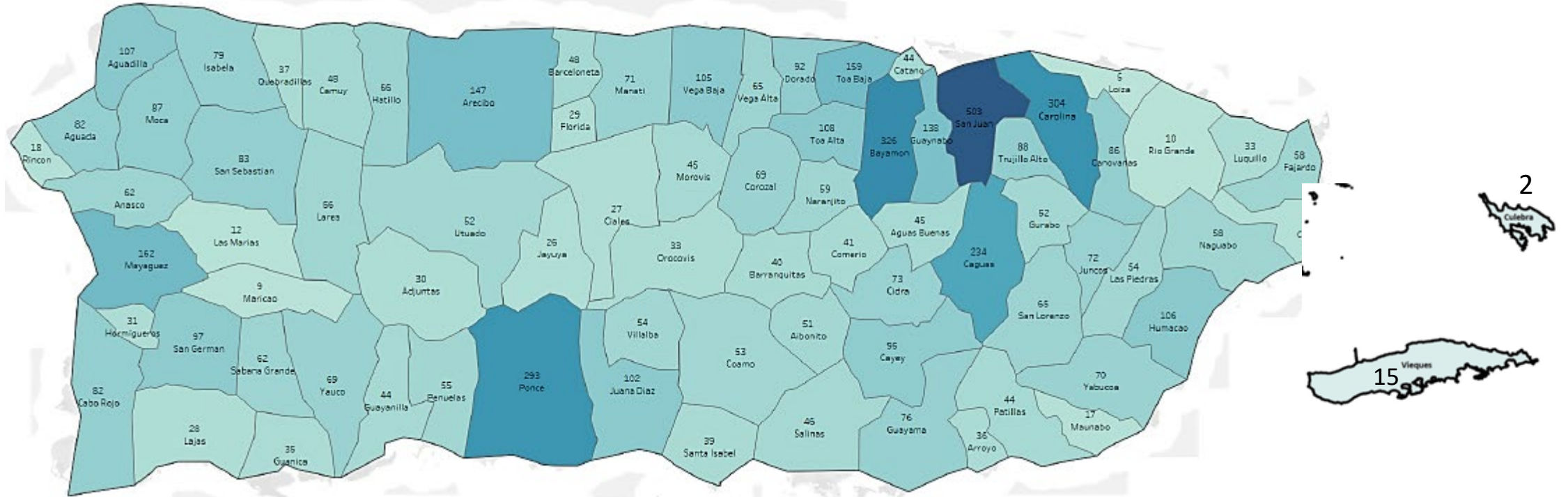


Companies / Organizations

Currently, the following companies and organizations are part of this coalition:

- Fresenius Kidney Care
- Centro Renal Pediátrico
- Centers for Medicare and Medicaid Services CMS
- Centro Renal Universitario
- Pure Life Renal of San Juan
- Consejo Renal de Puerto Rico
- Fundación Puertorriqueña del Pulmón.
- Metro Dialysis Care
- Quality Insights Renal Network

Map of dialysis population by municipality



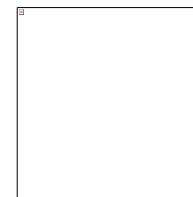
Geographic Location of Pediatric Dialysis Patients



Localización geográfica de nuestros pacientes actuales.



Centro de diálisis renal pediátrico.

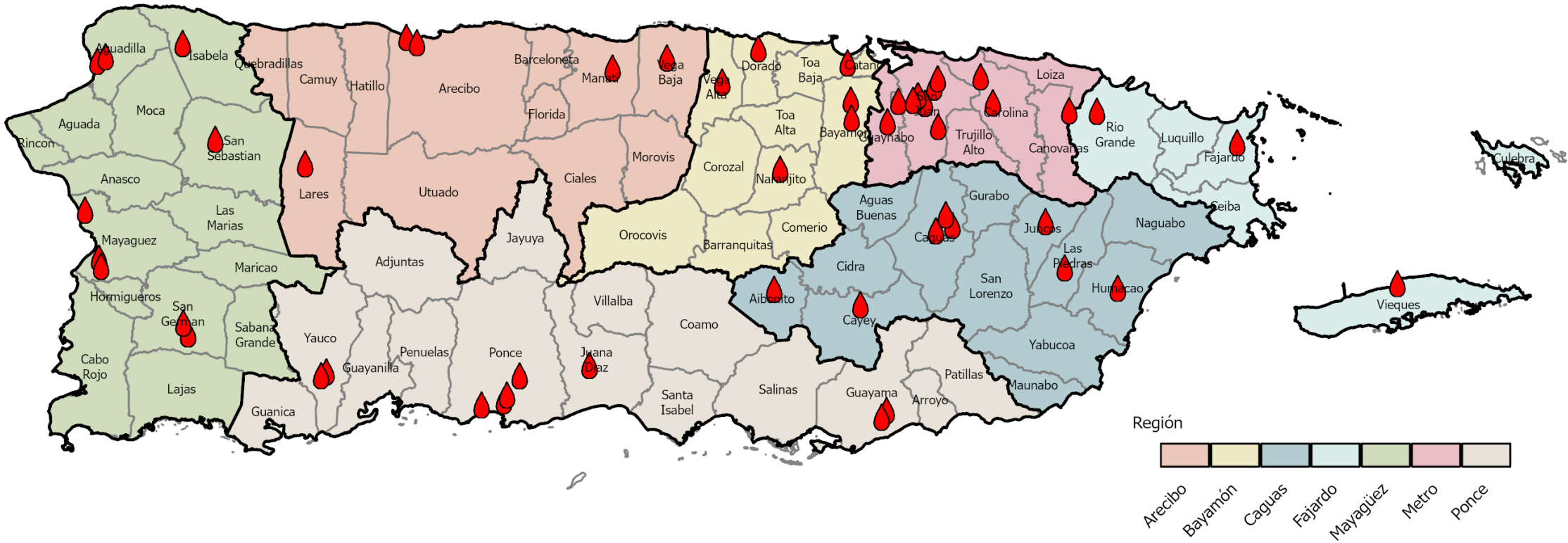


Predomina el transporte no emergente con compañía privada.



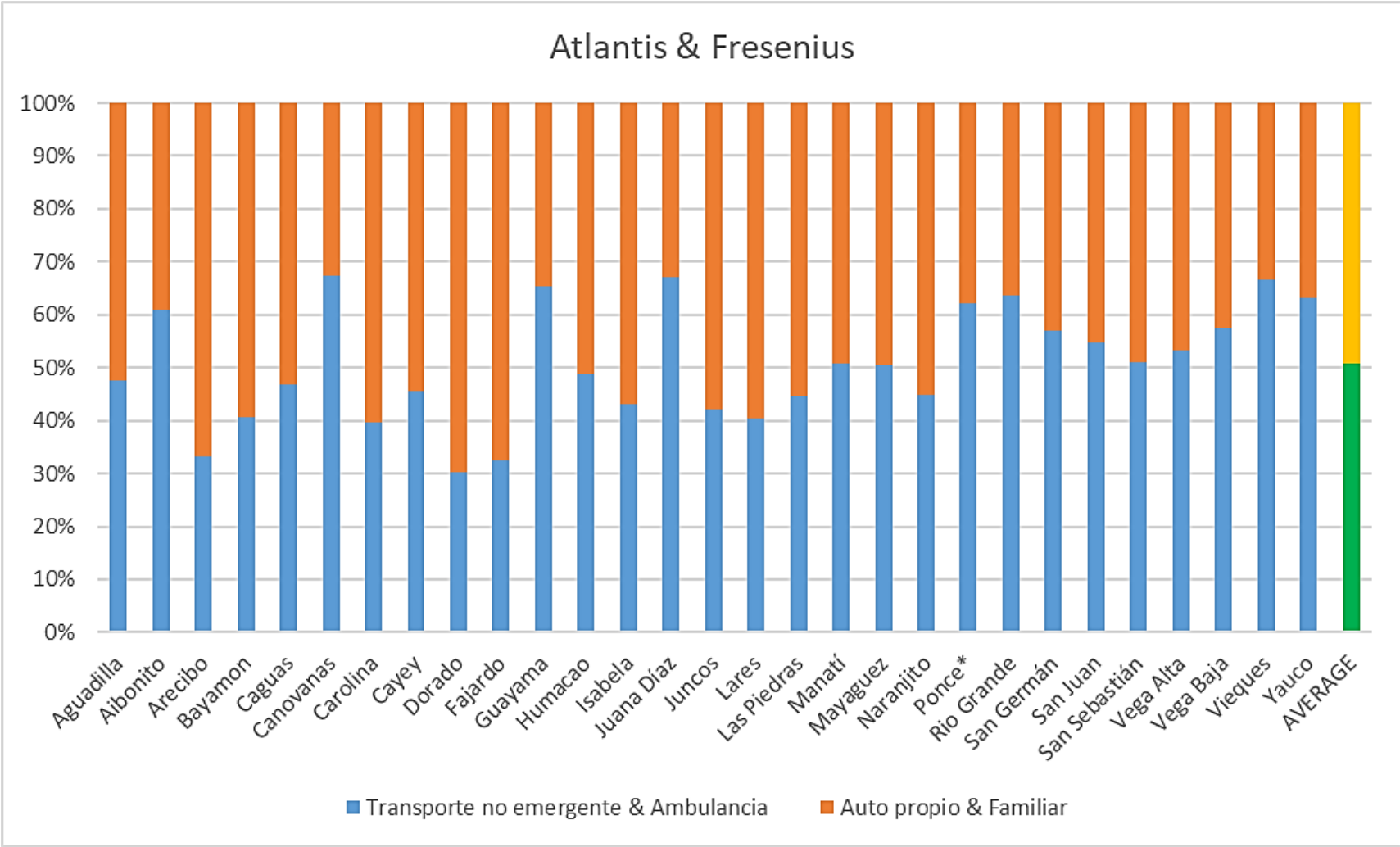
Transporte emergente.

Map of Dialysis Centers



03/2023

Dialysis Patients - Transportation Dependency



Training and Drills

- Staff Training
- Emergency response training for healthcare providers.
- Regular drills to practice emergency protocols.

Staff / Health Providers Training and Drills

- Tabletop exercises.
- EMResources platform to collect Essential Elements of Information EEI.
- HHS emPOWER platform to assist government agencies and organizations with a role in the emergency to locate people at risk during an emergency.

Puerto Rico Emergency Preparedness and Response Activities Renal Coalition (PREPARAR-C)



- Established in 2014 – ESRD Network 3 conducted its annual KCER tabletop exercise in Puerto Rico joined by dialysis and community stakeholders.
- Conducted multiple tabletop exercises and after-action reviews with all dialysis providers to test and establish improvement plans to strengthen future emergency response
- WhatsApp Group Chat!
- Group has activated several times over the years:
2015 Drought, 2016 Large power outage, 2017 Hurricanes Irma & Maria, 2020 Earthquakes and COVID-19 Pandemic, 2022 Island wide power outage, 2022 Hurricane Fiona, 2024 Ernesto Storm.
- Joint effort with PR DOH to develop the “*Plan de Respuesta Para el Manejo de Pacientes de Diálisis en Puerto Rico Durante Emergencias*” in 2023.

- *Fresenius Medical Care (FMC)*
- *Atlantis Healthcare Dialysis Group*
- *University Hospital Renal Center*
- *University Hospital Pediatric Renal Center*
- *Metropolitano Hospital Renal Center*
- *Auxilio Mutuo Transplant Center*
- *Renal Council of Puerto Rico*
- *Puerto Rican Kidney Foundation*
- *Puerto Rico Department of Health Office of Public Health Preparedness & Response (Biosecurity)*
- *Puerto Rico Department of Health Office of Regulation and Accreditation of Healthcare Facilities (SARAFS)*
- *U.S. Department of Health and Human Services (HHS)*
- *FEMA*
- *Centers for Medicare & Medicaid Services (CMS)*
- *End Stage Renal Disease (ESRD) Network 3*
- *Trans Cita*
- *Home Care & Hospice*
- *Subject Matter Experts – Nephrologist*

Collaboration with Agencies

- Partners in Emergency Preparedness
- Collaboration with FEMA, local hospitals, and community organizations who provides services to the at-risk population.
- Establishing a network for resource sharing.

Recovery Plan

- Post-Emergency Care
 - To ensure the safety and continuity of care for dialysis patients during emergencies.
- Follow-up protocols for affected patients.
 - The importance of the trainings and drills to keep updated the protocols for the kidney population.
- Assessment of health outcomes and adjusting plans as necessary considering the magnitude of the event or emergency and the needs for the kidney population.

Conclusion

- While identifying the dialysis population and their needs during an emergency, it is important to plan, develop and practice preparedness and response plans for events that may put the renal population in Puerto Rico at risk.
- It becomes relevant the importance of preparation and collaboration to ensure patient safety and care continuity.
- It would be important to include dialysis emergency partners in the implementation of emergency preparedness and response plans.

Questions and Discussion

References

Centers for Disease Control and Prevention (CDC).

Title: Emergency Preparedness and Response

URL: CDC Emergency Preparedness

Description: Provides guidelines and resources on emergency preparedness specific to healthcare settings.

National Kidney Foundation.

Title: Disaster Preparedness for Kidney Patients

URL: NKF Disaster Preparedness

Description: Offers resources and recommendations for kidney disease patients during emergencies.

Puerto Rico Department of Health.

Title: Emergency Management and Response

URL: Puerto Rico Department of Health

Description: Local guidelines and resources specific to health emergencies in Puerto Rico.

References

American Society of Nephrology (ASN).

Title: Resilience in Kidney Care: Preparing for Emergencies

URL: [ASN Emergency Preparedness](#)

Description: Discusses strategies for kidney care providers and patients to manage care during emergencies.

World Health Organization (WHO).

Title: Emergency Preparedness and Response

URL: [WHO Emergency Preparedness](#)

Description: Guidelines and resources for global emergency preparedness, including healthcare strategies.

Federal Emergency Management Agency (FEMA).

Title: Emergency Management and Response

URL: [FEMA](#)

Description: Provides a framework for emergency management and resources for disaster preparedness.

References

National Institute of Health (NIH).

Title: Addressing Health Disparities in Dialysis Care

URL: NIH Dialysis Care

Description: Research and findings on disparities in health care for dialysis patients during emergencies.

Hernandez, E. (2020).

Title: Emergency Preparedness for Chronic Kidney Disease Patients in Puerto Rico.

Journal: Puerto Rico Health Sciences Journal.

Description: A study focusing on the unique challenges faced by kidney disease patients during disasters in Puerto Rico.

Thanks for your attention!

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