

Distribution of Multiple Sclerosis in Puerto Rico: Important Hurricane Maria Aftermath

Angel Chinea^{1,2,4}, Astrid Diaz ^{1,3}, Cristina Rubi¹, Allan Reyes¹, Alejandro Melendez⁴, Ivonne Vicente^{1,2}

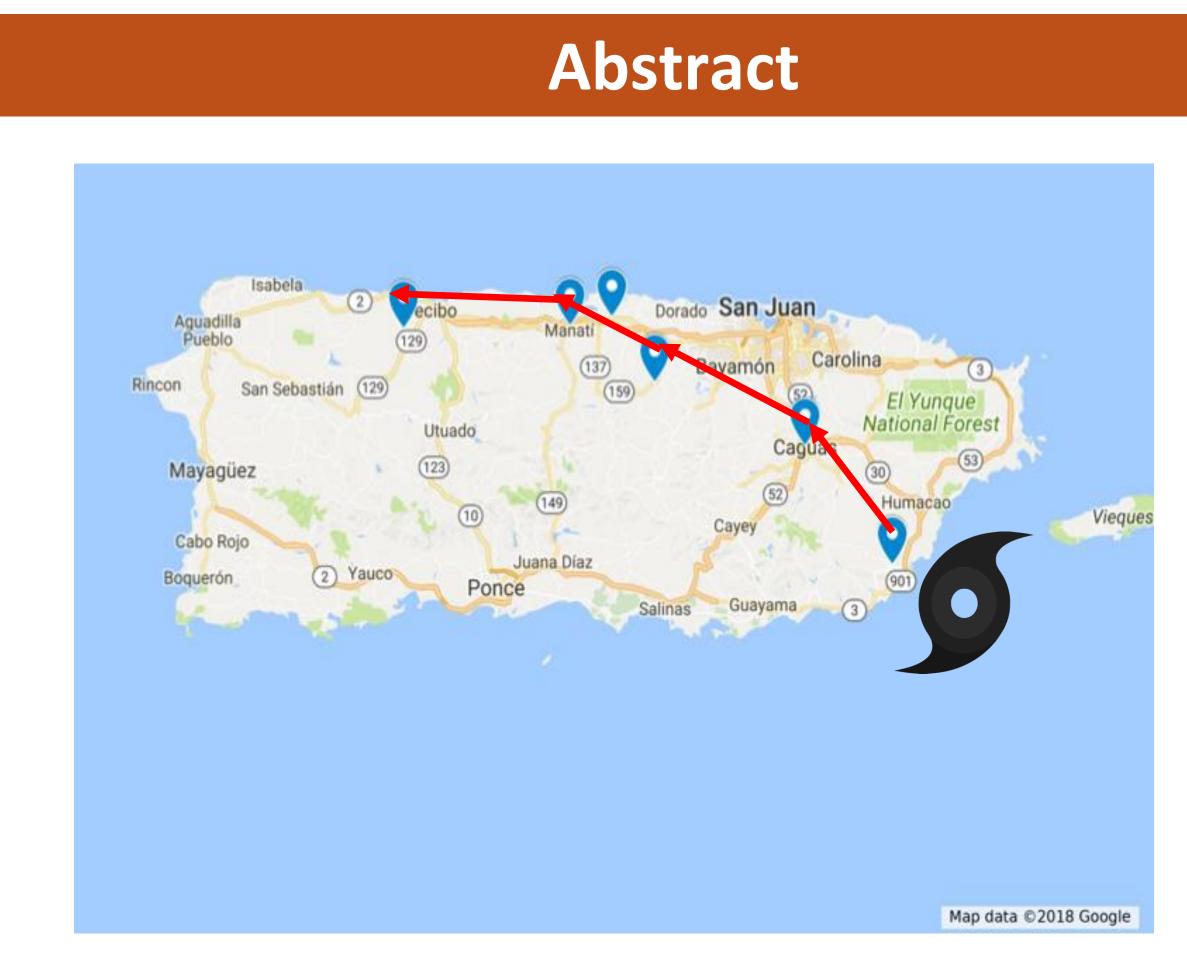


Figure 1. Hurricane Maria path through Puerto Rico.

The Puerto Rico Multiple Sclerosis (PRMS) registry has allowed for the mapping of MS patients across PR through the implementation of zones. This allows for targeted assignment of treatments and aids to the most affected zones. This registry has been fundamental in establishing that PR has a high MS prevalence and incidence (70.1/100,000 persons and 6.7/100,000, respectively)¹ when compared to Latin American countries. Hurricane Maria, the worst natural disaster in the history of PR, devastated the island on September 20, 2017, leaving many individuals without basic needs. It also left them without modes of communication because 62% of the municipalities did not have cellular signal. According to official government statements, 90% of the island was left without power including healthcare providers and emergency response hospitals. More so, access to medication was paralyzed. This all caused patients to have less than optimal living conditions to control MS symptoms. In some cases, this even led to relapses. The goal of this study was to establish how the PRMS registry helped provide relief efforts after Hurricane Maria. The PRMS registry was used to establish the location of MS patients across PR. 2049 patients were identified. For the purpose of the registry, the island was divided in 7 zones. Each one has an assigned support group and zone leader to help MS patients cope with their disease. Zone 1, the metropolitan area, has the highest concentration of MS patients (45%). In this area, the services were reestablished faster and people had more available resources (i.e, PR MS Foundation and medical partners), which were used to better help hurricane • devastated patients. These resources where then used to aid the most affected and medical partners formed support networks that helped fulfill the needs of many of the patients. This validates the importance of an MS registry and a plan for future emergencies.

Objective

Establish how the PRMS registry helped provide relief efforts after Hurricane Maria

1 San Juan MS Center, 2 San Juan Bautista School of Medicine, 3 University of Puerto Rico Medical Sciences Campus, 4 Puerto Rico MS Foundation

Methods

The PRMS registry was used to establish the location of MS patients across PR. 2049 patients were identified. The island was divided into 7 zones for simplification. Zone 1 is the metropolitan area. Zones 2, 6, and 7 were the most affected by the hurricane (Figure 2).

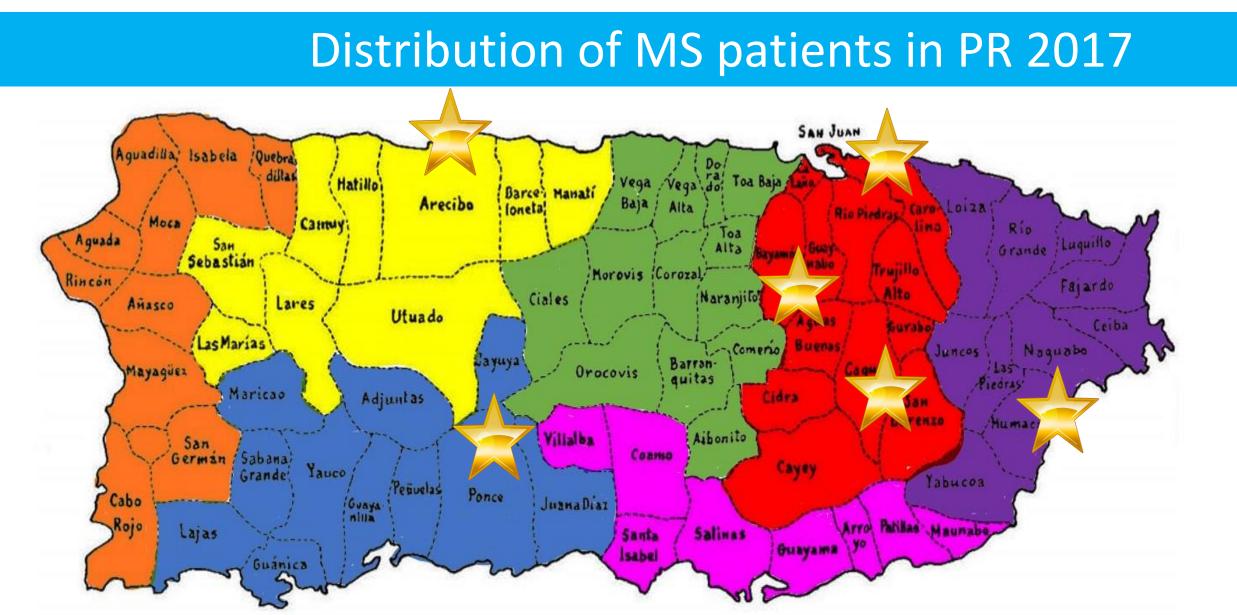


Figure 2. Distribution of MS Patients in PR 2017 indicated by zones and color. Yellow stars represent the established distribution sites

Zone 1	Zone2	Zone 3	Zone 4	Zone 5	Zo
44.15%	12.2%	9.8%	10.96%	9.26%	3.3

Funding Organization	Type of Funding
Unidos por Puerto Rico	\$ 43,000
Fundación Comunitaria de PR	\$ 5,373
Multiple Sclerosis Foundation	Battery Fans Cooling vest
Others	Non Perishable Food Boxes Cooling pads Water bottles

Figure 3. Types of funding provided to the PRMSF

- Hurricane Maria caused the worst devastation of the century in Puerto Rico.
- We were not prepared and it has been evidenced by the destruction of our electric system,
- infrastructure and hospitals, among others.
- The PRMSF registry enabled the effective distribution of aid to our patients. \bullet
- zones with the most affected MS patients. Furthermore, the MS Foundation Future work will include the development of a standing operating procedure (SOP), which will include a detailed protocol to follow after a catastrophe.
 - Alliances between the PRMSF, neurologists, pharmaceutical companies, and other healthcare providers will be organized to be able to reach the majority of our patients in case of an event like
 - this one.
 - We aim to motivate other countries to establish emergency management protocols to be more effective after events of this magnitude.
 - acquisition of DMTS and proper follow up treatment in other states.



The immediate help consisted of:

- Making medication available to patients. samples to the island via private courier and in person.
- Identifying resources, open sites, and pharmacies. assist.
- To provide services to patients in need of monthly infusions and treatment for relapses. operated 24 hours a day to preserve the MS medication.

Additionally

- of the island.
- Rico" to help patients that had lost their homes and appliances (Figure 4).

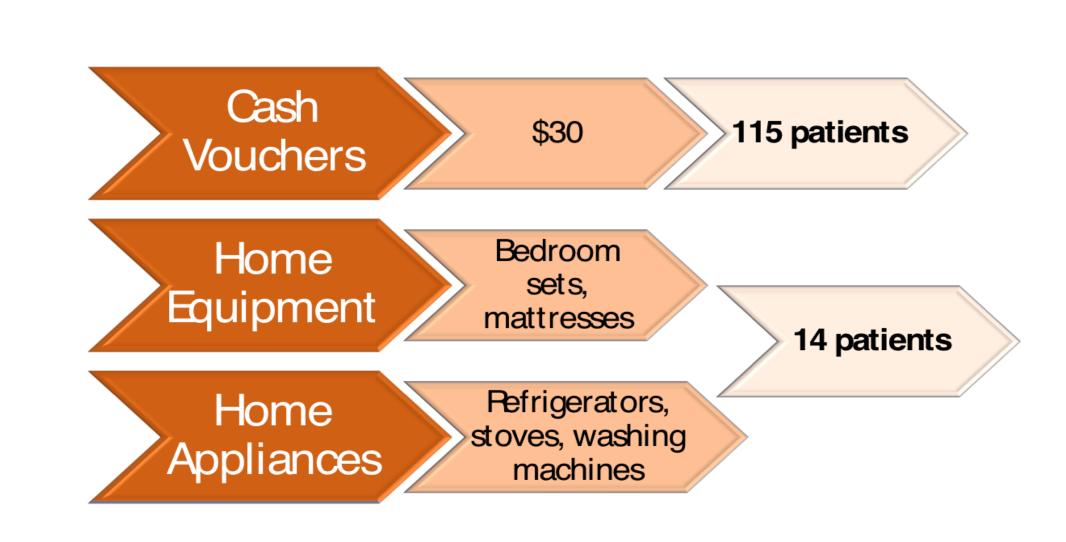


Figure 4. Shows some of the aid provided to patients.

Conclusion

Zone 7

9.55%

34%

15% of the population migrate^{,2} to USA. We need to consider how MS patient migration will affect the



PF07

Results

PRMSF Medical Director, Dr. Angel Chinea, and San Juan MS Center requested assistance and medication samples for oral DMTs from pharmaceutical companies. Sanofi, Novartis, and Biogen in Miami brought

A network of medical representatives and health associates available at the Metropolitan area volunteered to

Special Care Pharmacy in the metropolitan area established an Infusion Center. This Center's diesel generator

Funds were obtained to provide patients non-perishable food, water, and other basic necessities (Figure 3 - 4). The PRMSF Executive Director, Lourdes Fernandez, established distribution centers in various physician s offices

The MS Foundation also received funds from "Unidos por Puerto Rico" and "Fundación Comunitaria de Puerto



Figure 5. Houses of patients severely affected by the hurricane.





References

- Chinea A et al Increasing Incidence and Prevalence of Multiple Sclerosis in Puerto Rico (2013-2016)Neuroepidemiology 2017 Nov 14;49(3-4):106-112. doi: 10.1159/000484090
- Melendez, E., Hinojosa, J. 2017. Estimates of post-Hurricane Maria Exodus from Puerto Rico. Center for Puerto Rican Studies

Disclosure

None of the authors of this research received any grants or monetary compensation.

For more information: achinea@me.com