

# Educating Spanish-speaking Communities About Parkinson's Research Participation and Genetics: A Community Health Worker (*Promotores*) Model for Outreach

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## Objective

The objective of this project was to prepare *promotores* to educate Spanish-speaking communities about Parkinson's disease (PD), research participation and genetics.

## Background

Hispanic PD communities are less likely to see a specialist and are underrepresented in research.<sup>1,2</sup> A best practice for addressing gaps in knowledge, resources and support in Hispanic communities is Spanish-language, peer-to-peer education. *Promotores* are Hispanic/Latino community members who are trained to improve quality of life in their communities through health education. However, no standardized Spanish-language PD training for *promotores* exists. Parkinson's Foundation and community partners addressed this gap by creating a pilot *promotores* training.

## Methodology

Parkinson's Foundation, Muhammad Ali Parkinson Center Hispanic Outreach Program and *promotores'* organizations from the southwest created a standardized Spanish-language PD program to train 50 *promotores* in educating their communities. The program included presentations by researchers, clinicians and community engagement professionals on PD basics, an overview of research and genetics, and resources from the partner organizations. Patient advocates and *promotores* representatives presented on research participation and case examples of community outreach. Participants created outreach plans. Pre/post assessments were conducted on knowledge, attitude and intentions regarding PD, research and genetics.

## Results

In pre/post tests, increases were seen in agreement that knowledge of genetics can help find better treatments for PD (82%/96%) and identify who is at risk (89%/100%) and that Hispanic communities would be interested in genetic testing (54%/74%). Participants felt confident sharing information with the PD community (91%) after the program. They also agreed that information received was useful, new and important. Participants identified outreach opportunities at festivals, farmers markets, churches and senior centers.

## Conclusion

This pilot demonstrates that a standardized, Spanish-language PD *promotores* training brings new, important information to Hispanic communities and makes a positive impact on knowledge and attitudes towards genetics. Next steps to expand this work include continuing education for *promotores*, evaluation of community outreach and replication of the program.

Figure 2: Change in *Promotores* Attitude Toward Genetic Testing n = (50)

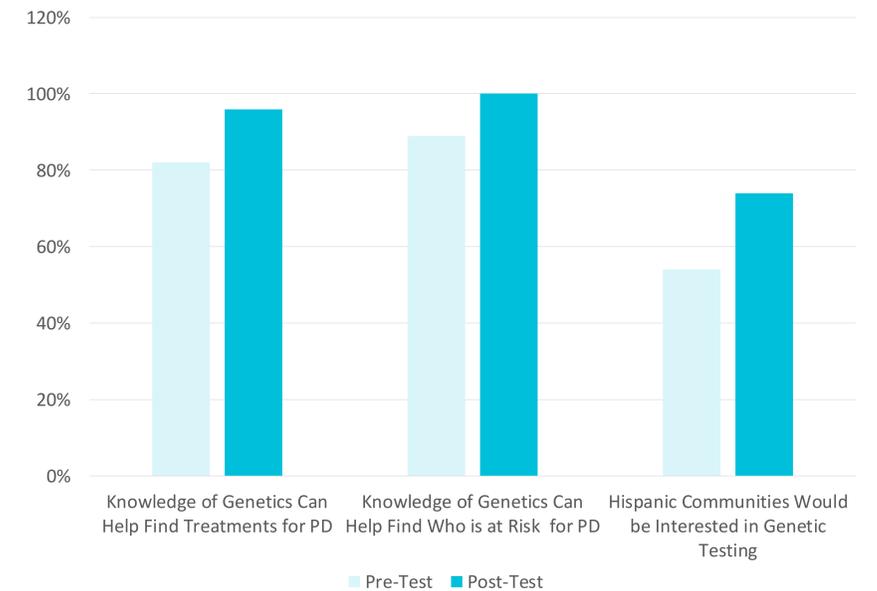


Figure 3: Quality of Training n = (50)

Statement	Average Likert Scale Rating
I received useful information through this training.	4.7
I received new information through this training.	4.8
I received important information through this training.	4.8

A 5-point Likert Scale was used with 4 being Very Good and 5 being Excellent

### Citations

1. Schneider MG, Swearingen CJ, Shulman LM, Ye J, Baumgarten M, Tilley BC. Minority enrollment in Parkinson's disease clinical trials. *Parkinsonism Relat Disord.* 2009;15:258-262.

2. Willis AW, Schootman M, Evanoff BA, Perlmutter JS, Racette BA. Neurologist care in Parkinson disease: a utilization, outcomes, and survival study. *Neurology.* 2011;77:851-857.

Figure 1: Demographics of *Promotores*

<b>States Represented</b> 	<b>Organizations Represented</b> <ul style="list-style-type: none"> <li>• 18 Agency <i>Promotores</i></li> <li>• 15 Hospital/Health Care System</li> <li>• 12 Independent <i>Promotores</i></li> <li>• 5 Community Services</li> </ul>
<b>Gender</b> <ul style="list-style-type: none"> <li>• 44 Women</li> <li>• 6 Men</li> </ul>	