Working Group Focus
The Reaching the Newly Diagnosed Working Group (Working Group) focused its presentation on the role stigma and shame play as a barrier to communicating with people with Parkinson’s (PwPs) who are recently diagnosed. The resulting difficulty in reaching this group often results in the PwPs not getting the care and information they need.

Poll Questions
The Working Group posed two poll questions to those in attendance.

1. Is stigma and shame an issue in your country for PwPs?
   Results: 88% Yes, 7% Not Sure, 5% No

2. Please rate the severity from 1 (there is little to no stigma associated with Parkinson’s) to 10 (there is severe stigma that inhibits PwPs from telling anyone about their condition) in your country.
   Results: More than 50% rated severity at 6 or greater

Interview Overviews
Working Group members conducted interviews with members of the Parkinson’s community in different regions. Some of their key findings:

Europe
- Stigma is a common theme in this region of the world, especially in more traditional countries like Italy.
- The region is very diverse and each country is different economically, traditionally, culturally, and socially, and these are all important factors that affect the stigma around PD.
- Industry organizations often lack the resources to reach out to the newly diagnosed population and develop tailored programs.

Taiwan and Malaysia
- Like Europe, these Asian countries contain a remarkably diverse set of cultures, religions, and languages.
- These factors all affect whether PwPs share their diagnosis, when they share their diagnosis, and where they seek care.
Breakout Groups
The session broke out into groups to discuss the following:

- Should we look at a global campaign to address stigma and Parkinson’s?
- If “no,” what are other options?
- If “yes” and we could get funding to do this, what would it look like?
- How would we ensure we have a campaign that is culturally appropriate globally?
- How would we deploy this and what barriers would we encounter?
- Would your organization be interested in being part of an anti-stigma campaign around Parkinson’s?

Breakout Group Highlights

- It’s important for the community to acknowledge Parkinson’s as a global pandemic and perhaps begin working with the World Health Organization on a campaign.
- The Parkinson’s industry and HCPs are key audiences for an awareness campaign to ensure they aren’t contributing to the stigma of Parkinson’s.
- A source of funding for the campaign may be the pharmaceutical industry.
- An awareness campaign also should focus on combating the stereotype that Parkinson’s is an “old person’s disease.”
- To address the challenge of tailoring the message of an awareness campaign to the different countries, a “multi-level” campaign was proposed — i.e., a campaign that easily could be customized depending on the country’s existing level of awareness and stigma.
- There is a need to determine and define what “stigma” means in different countries and cultures.
- Other organizations want to collaborate and share information regarding the campaign.
- It’s critical to align with other organizations that are addressing this issue globally, and PD Avengers would be an appropriate potential collaborator.
- PwPs in the breakout rooms do not like the word “disease”; they proposed it may be time to look at the stigma around “disease” and consider how we talk about Parkinson’s to the world.

What’s Next
The Working Group is seeking help. Audience members are encouraged to contact the Working Group if they’d like to add to the conversation around stigma and shame, contribute to the development and implementation of the awareness campaign, or join the general Working Group.

Questions for the Technology Working Group?
Contact Jean Blake at jblake@parkinson.bc.ca

Questions for the WPC?
Contact Elizabeth Pollard at eli@worldpdcoalition.org

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