Definition of Young Onset Parkinson’s Disease (YOPD)
YOPD is defined differently around the globe, with age-of-diagnosis ranging from 40 and younger to 60 and younger. Until a globally accepted definition or more specific categorizations are established, the Working Group defines those with YOPD as People with Parkinson’s (PwPs) who were diagnosed at age 50 or younger.

Why A YOPD Working Group
YOPD is misunderstood, under-represented, and often misrepresented. Decision makers have a perception that Parkinson’s (PD) is an old person’s disease. YOPD is recognized as very different from the larger PD community, yet it has not been described well epidemiologically or clinically. *

The YOPD community is a largely untapped, energetic, and motivated resource for researchers and organizations. They are:
- Living with the disease for 30+ years, making them a rich source for long-term research
- Tech savvy
- Driven, engaged, and interested
- A focused and powerful tool toward progress
- Appealing to media outlets for their novelty and affecting stories
- Connected to a similarly engaged community of care partners and family members
- Offering rare and unique data that can be advantageous from a research perspective
- For all of the above reasons, an asset to the larger PD community
The impact of YOPD is perhaps wider than generally recognized. Many with YOPD are not diagnosed or misdiagnosed for years. This leads to ineffective treatments, frustration, anxiety, depression, etc. Even once diagnosed, the impact of the disease is felt by the family, future generations, and society. With limited treatments available and longer disease progression, greater understanding and management of medication is essential. A long-term, multi-disciplinary care plan needs to be determined and implemented with both health care professionals and patient input, ensuring a better quality of life.

Areas in which others can get involved with the YOPD Working Group

The Importance of Research
The Working Group supports research fuelled by genome sequencing to identify more genetic types of YOPD. Phenotypically and genotypically classifying PD will focus research efforts leading to better treatments, something the YOPD community is eager to see realized. To that end, the Working Group is engaged in global YOPD patient engagement through the World Parkinson Coalition. They are asking select researchers and organizations around the globe to work with them on genetic testing and sharing information.

The YOPD Promise Survey
To assist with the collection of data related to YOPD, the Working Group will launch a YOPD global survey called The YOPD Promise Survey — Patient Research On Medication, Information, Symptoms and Experience. It is the first of its kind, designed by and for people with YOPD and incorporating the patient’s voice at every stage of development and implementation. It will contain questions on a series of topics as identified by a sub-group. The survey will be an ongoing, ever-evolving study hosted on the REDcap platform. The Working Group’s goal is to collect information from at least 1,000 respondents, with a minimum of 500 respondents. Its launch is expected late 2021 or early 2022. The resulting data and results will be made available to researchers and organizations interested in YOPD issues.

The Working Group recognizes it is critical that this survey reflect the global nature of YOPD and the many ethnicities and cultures therein. It is intended to be distributed to as many countries in which people with YOPD live and function as possible. With that in mind, the Working Group needs partner organizations and the many enthusiastic supporters connected to the WPC to help with distribution and translation.

Women and YOPD
There is evidence that YOPD symptoms (motor and non-motor) are affected and possibly exacerbated by hormonal fluctuations associated with menstrual cycles and the ineffectiveness of PD medications during this time. There is very limited information about this, so it is poorly addressed and often unrecognized, even by Movement Disorder Specialists (MDS), OB-GYNs and other care providers. In scientific literature, only 5% of YOPD papers mention menstruation
and 15% mention pregnancy. Only 23% mention women. Women are included in research studies, but they are not being asked questions based on age, resulting in limited hormone-related information.

Currently there is a keen and growing awareness of the unique issues faced by women with YOPD, as well as great interest in supporting progress and research to help address them. The Working Group is seeking ways to begin to do this, and it acknowledges that there are other organizations working towards a similar goal. Related questions will be included in the YOPD Promise Survey, including questions about the effects of oral contraception, PD medications other than Levodopa, and unique lifestyle considerations (e.g., career, family, etc.).

Care teams should begin to make the following questions part of routine visits with women with YOPD:

1) How are hormone fluctuations (menstrual, perimenopause) affecting your PD symptoms?
2) Are you tracking your PD symptoms and menstrual cycles — e.g., using apps like Clue
3) How have your menstrual cycles changed since we last met? Have your PD treatments been affected by your menstrual cycle? Has your menstrual cycle been altered by your PD treatments?

For YOPD women, we encourage you to discuss with your care team:

1) How your menstrual cycle impacts your PD symptoms and if your cycle has changed since diagnosis.
2) How your menstrual cycle affects the efficacy of your medication.

*The Working Group recognizes an exception to this is:

Questions for the YOPD Working Group?
Contact Gaynor Edwards at gaynor@spotlightyopd.org

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

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