

# Understanding How Doctors See Your Parkinson's Disease

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[www.gsfriedman.com/xxxxxxdouts/PDVS.pdf](http://www.gsfriedman.com/xxxxxxdouts/PDVS.pdf)



## Goals for today's talk

The PDRS and other evaluation scales

Why you might need to change the  
**doctor who treats your Parkinson's**

How to select a new Movement  
Disorders Specialist

First a few housekeeping items

Mission Statement

Palm Beach NPF

**World Parkinson's Congress 2019**

Parking

Emails



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# Parkinson's Disease Rating Systems

Does your doctor ask you to self rate

Standardization

Tracking

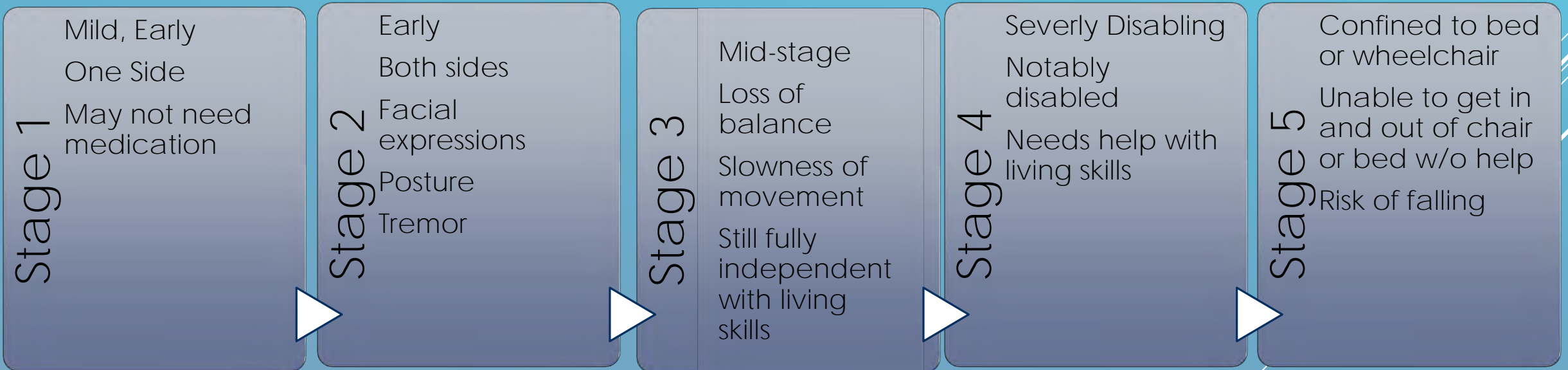
## MDS-Owned Rating Scales

- [Global Assessment Scale for Wilson's Disease](#) | [Scale](#)
- [Global Dystonia Scale](#) | [Scale](#)
- [Modified Bradykinesia Rating Scale](#) | [Scale](#)
- [Non-Motor Symptoms Scale \(NMSS\)](#) | [Scale](#)
- [Non-Motor Symptoms Questionnaire \(NMSQ\)](#) | [Scale](#)
- [PKAN Disease Rating Scale \(PKAN-DRS\)](#) | [Scale](#)
- [Quality of Life Essential Tremor Questionnaire](#) | [Score Sheet](#)
- [Rating Scale for Psychogenic Movement Disorders](#) | [Scale](#)
- [Rush Dyskinesia Rating Scale\\*](#) | [Scale](#)
- [Rush Videobased Tic Rating Scale](#) | [Scale](#)
- [UFMG Sydenham's Chorea Rating Scale \(USCRS\)](#) | [Scale](#)
- [Unified Dyskinesia Rating Scale \(UDysRS\) + \\*](#) | [Scale](#)
- [Unified Dystonia Rating Scale \(UDRS\)](#) | [Scale](#)
- [Unified Multiple System Atrophy Rating Scale \(UMSARS\)](#) | [Scale](#)
- [Unified Parkinson's Disease Rating Scale \(MDS-UPDRS\) + \\*](#) | [Scale](#)

*Note: Asterisk (\*) indicates scale was developed by MDS.*

# The Hoehn and Yahr scale

## Stages of Parkinson's



# Unified Parkinson's Disease Rating Scale

## Original

- 4 parts
- Each item scored:
  - 0 no problem
  - 1 minimal problem
  - 2 mild problem
  - 3 moderate
  - 4 severe

## Updated 2001

- Involve patients and caregivers

## Updated 2008

- Expanded to more sections

# Unified Parkinson's Disease Rating Scale

Part 1 Intellectual function,  
mood, and behavior

Forgetfulness

Vivid Dreams

Hallucinations

Depressed  
Mood

Anxious Mood

Apathy

Sleep Issues

Pain

Fatigue

Urinary

Constipation

# Unified Parkinson's Disease Rating Scale

## Part 2 Activities of Daily Living

Speech

Drooling

Swallowing

Cutting  
Food

Small  
Handwriting

Getting  
Dressed

Personal  
Hygiene

Turning in  
bed

Tremor

Getting in  
and out of  
bed

Walking

Freezing



# Unified Parkinson's Disease Rating Scale

## Part 3 Motor Exam

Volume of  
Speech

Facial  
Expression

Rigidity

Finger  
Tapping

Slow hand  
movements

Toe Tapping

Agility

Getting up  
from chair

Gait

Posture

Spontaneous  
Movement

Tremor at rest

# Unified Parkinson's Disease Rating Scale

## Part 4 Motor Complications

Dyskinesia

Motor  
Fluctuations  
(on/off)

Complications  
of Therapy

# Unified Parkinson's Disease Rating Scale

## Part 5 Hoehn and Yahr Staging

Stage 0

- No Sign of Disease

Stage 1

- Unilateral disease

Stage  
1.5

- Unilateral plus axial

Stage 2

- Bilateral without balance problems

Stage  
2.5

- Mild Bilateral with recovery on pull test

Stage 3

- Mild to moderate bilateral, some postural instability, physically independent

Stage 4

- Severe Disability, still able to walk or stand unassisted

Stage 5

- Wheelchair bound or bedridden unless aided

# Unified Parkinson's Disease Rating Scale

## Part 6 Schwab and England Activities of Daily Living Scale

100%

- Completely independent, unaware of any difficulties

90%

- Completely independent, Some chores might take longer

80%

- Chores take twice as long. Conscious of difficulty and slowness

70%

- Not completely independent. Can do most chores but very slow.

60%

- Can do chores but exceedingly slow and with errors, some are impossible

50%

- More dependent. Needs help, Difficulty with everything

40%

- Very dependent. Can do few chores alone.

30%

- With effort, occasionally does a few chores. Much help needed

20%

- Nothing alone. Can be a slight help. Severe invalid..

10%

- Totally dependent. Complete invalid

# Evaluation

See Worksheet

- For parts 1 to 4 scores are listed and totaled
- Some cases data is recorded for when medicines are on and off

Parts 5 and 6 are listed for trends

Can graph how these change over time

# [www.patientslikeme.com](http://www.patientslikeme.com)

Forum

Find People with similarities

Track symptoms

Track medicines

PDRS (Parkinson Disease Rating Scale)

Quality of Life

Doctor Visit Sheet

Moderated

Supports events like Moving Day

About Me

Hospitalizations

InstantMe

Labs & Tests

My Charts

My Conditions

MyCycle

My Symptoms

My Treatments

PDRS

Quality of Life

Weight

## My Charts



**sunshine221**

Female, 57 years  
Corning, NY

**Primary condition:** [Parkinson's](#) and 1 more

**Type:** Parkinson's disease

**First symptom:** Apr 2004

**Diagnosis:** Mar 2007

**Interests:** [Working with my Condition](#)

▶ See more

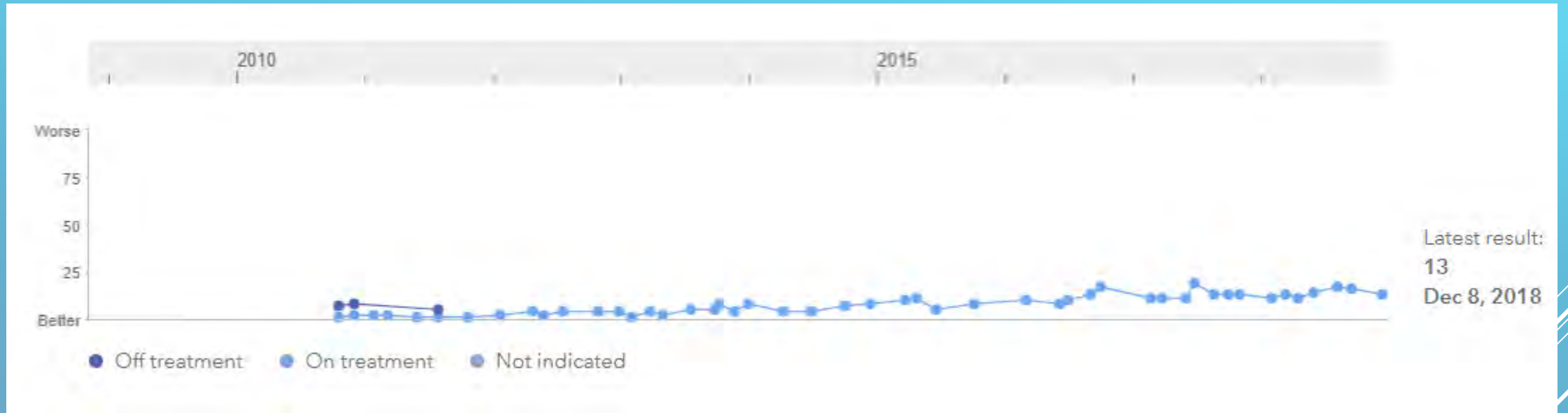
View



Ch

Showing Jul 14, 2015 - Oct 13, 2015

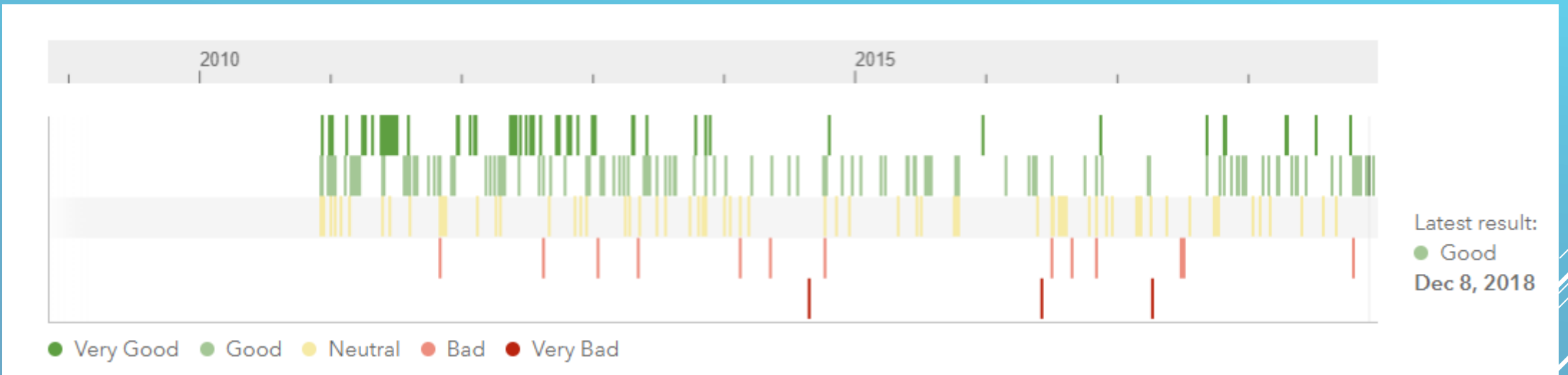
# PDRS Trends



Data from November 2008 to present

Range low is 2 highest is 19

# PDRS Trends



Data from November 2008 to present

Range low is 2 highest is 19



## Why to change doctors

Making a move to a new location

Uncomfortable with doctor or staff at current office

Being treated by someone other than a Movement Disorder Specialist

# How to find a new MDS

# Ask Questions

<https://www.partnersinparkinsons.org/find-movement-disorder-specialist>

Billing policies/insurance

Office hours

Change of medication and WHY

Clinical trials y/n

Emergencies

Prescription Renewals

DBS

Social Worker Available

Physical Therapy

Other



# Other sites

Research

Mayo Clinic

- [www.mayoclinic.org](http://www.mayoclinic.org)

Health Central

- [www.healthcentral.com](http://www.healthcentral.com)

World Parkinson's Coalition

- [www.worldpdcoalition.org](http://www.worldpdcoalition.org)

National Institutes of Health

- [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

SOCIAL / SHARING

[www.Parkinson.org](http://www.Parkinson.org)

Ask the Doctor

Ask the Pharmacist

Ask the Surgical Team

Ask About Nutrition

Talk to a Speech Clinician

Open Forum

Caregivers

DBS Forum

Young Onset Forum

The screenshot displays the Parkinson's Foundation website interface. At the top, there is a navigation bar with the logo, 'Call Our HELPLINE 1-800-4PD-INFO', and a 'DONATE' button. Below this, there are tabs for 'Forums' and 'Members', along with a 'View New Content' link. The main content area is titled 'Ask The Surgical Team' and includes a description of the forum's purpose. It features a 'Subforums' section with a link to 'Archive - 2011 Posts of the Week'. At the bottom, there is a 'Recently Updated' section listing several pinned posts with their respective authors, dates, and view counts.

Call Our HELPLINE 1-800-4PD-INFO

**DONATE**

Forums Members View New Content

Medical Questions Ask The Surgical Team

Sign Up For Our E-NEWSLETTER Like us on FACEBOOK

### Ask The Surgical Team

Kelly D. Foote, M.D. and Michael Okun, M.D. answer questions about surgical matters and Parkinson's disease. All posts in this forum are anonymous. Without seeing you and examining you the doctor cannot make specific diagnoses and recommendations. The suggestions given in this forum are for general information only.

Frequently Asked Questions - Step by step guides Posted by Forum Admin

#### Subforums

Archive - 2011 Posts of the Week 16 topics 17 replies Post of the Week: Why do pe... By Dr. Okun 12 Dec 2011

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#### Recently Updated

Start Date	Most Replies	Most Viewed	Custom
<b>PINNED</b> Post of the Week: New Study on Constant Current DBS Started by Dr. Okun , 14 Jan 2012	6 replies 2,445 views	Dr. Okun 18 Jul 2015	
<b>PINNED</b> Post of the Week: GPI DBS is Making a Comeback for Parkinson's Disease Started by Dr. Okun , 24 Jun 2012	8 replies 2,435 views	Dr. Okun 04 May 2015	
<b>PINNED</b> Post of the Week: STN DBS Worsens Language Function Started by Dr. Okun , 12 Aug 2012	11 replies 2,389 views	Dr. Okun 27 Feb 2015	

# QUESTIONS / DISCUSSION

