

How do I know if the Parkinson's educational resources I use are **trustworthy**?

1

OUR GOALS

Understanding the importance of being able to assess the information we access.

Recognizing the common challenges.

Learn key factors to determine trustworthiness

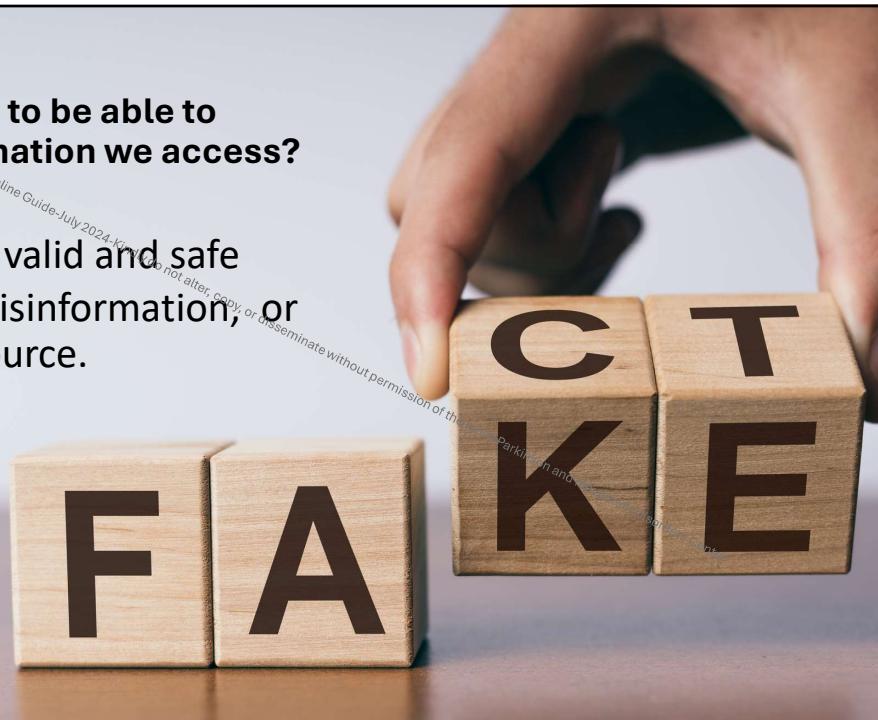
2

1

COPYRIGHT 2024 / MDC - Recently Disseased Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inje University and Movement Disorders Center

Why is it important to be able to evaluate the information we access?

- Information is valid and safe
- Not a scam, misinformation, or unhelpful resource.



3

COPYRIGHT 2009 / MDC - Recently Disseased Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inje University and Movement Disorders Center

Informatics for Health & Social Care
September 2009; 34(3): 136–148

informa
healthcare

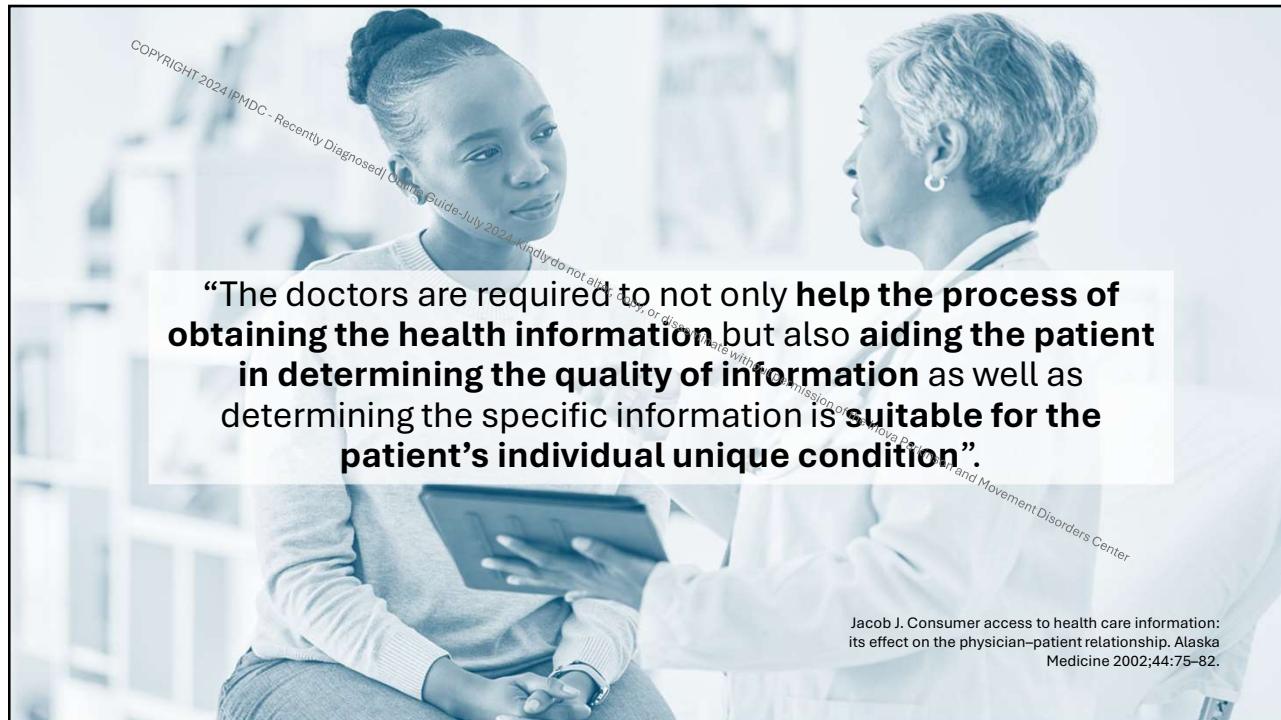
Physicians' perception of the effects of internet health information on the doctor–patient relationship

JEONGEUN KIM¹ & SUKWHA KIM²

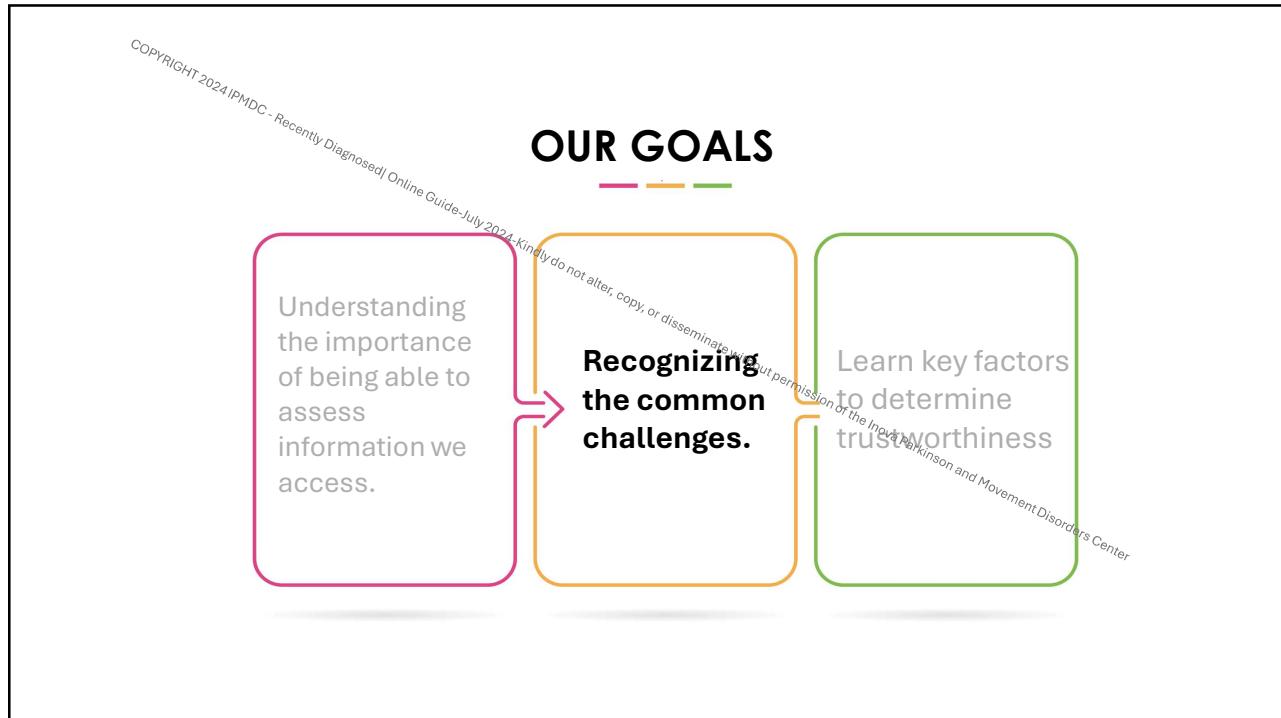
¹College of Nursing, Research Institute of Nursing Science and ²College of Medicine, Seoul National University, Seoul, Korea

- 81% of physicians have seen patients who made inquiries about information they found on the Internet.
- ++ Internet Health information may enhance the patient's knowledge about their health.
- -- Drs perceived that it may also have a variety of negative effects such as:
 - heightening the cost of health care by adopting inappropriate health service utilization (56.2%)
 - making the patients over-concerned about their health (74.5%)
 - damaging the time efficiency of the visit (60.9%).

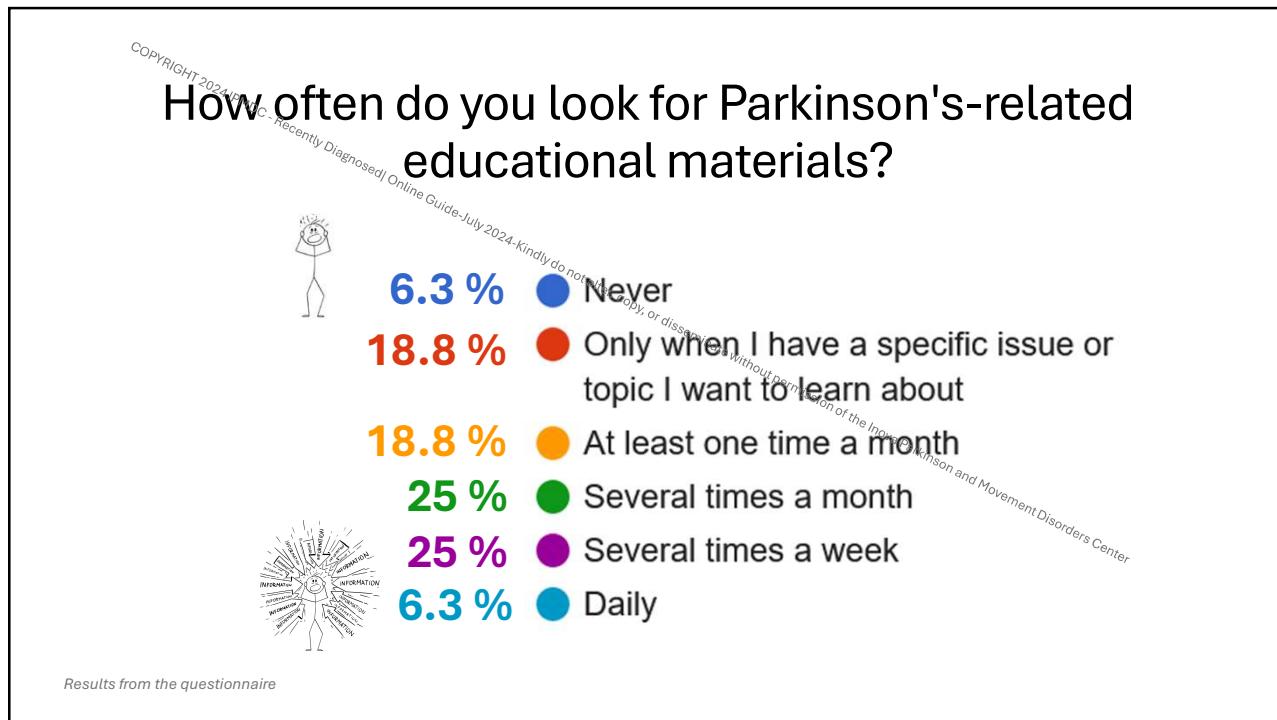
4



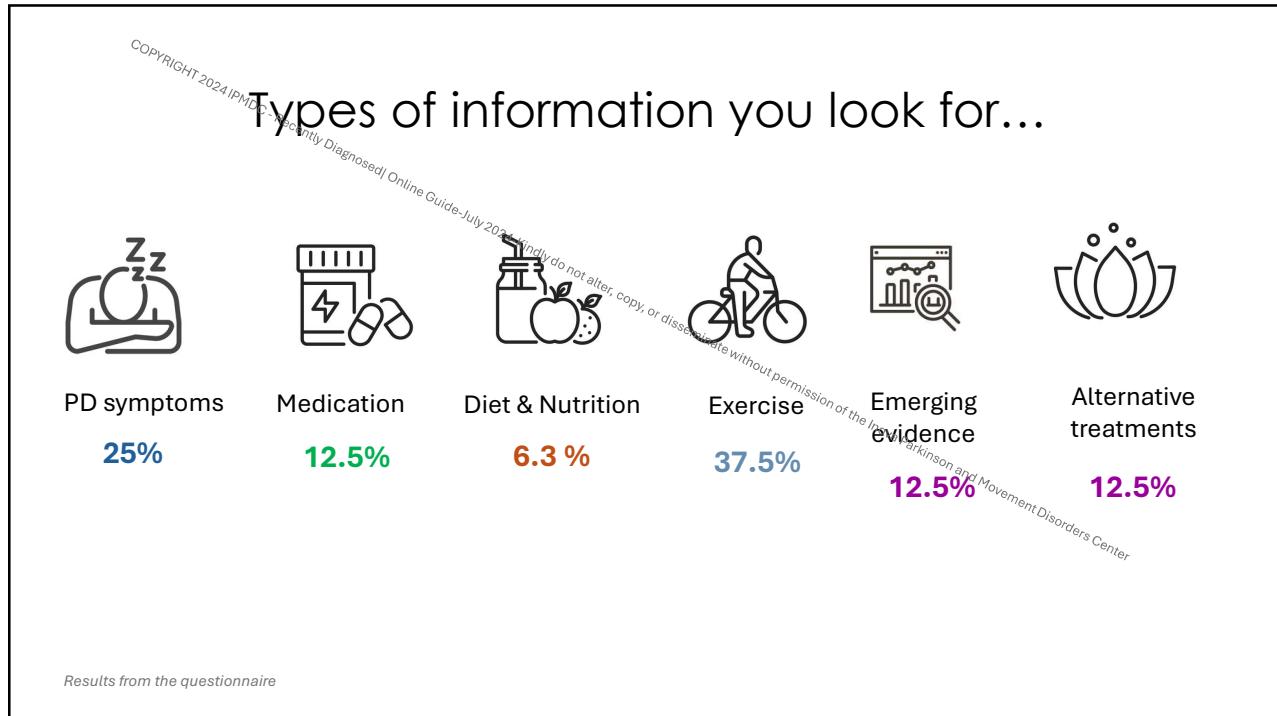
5



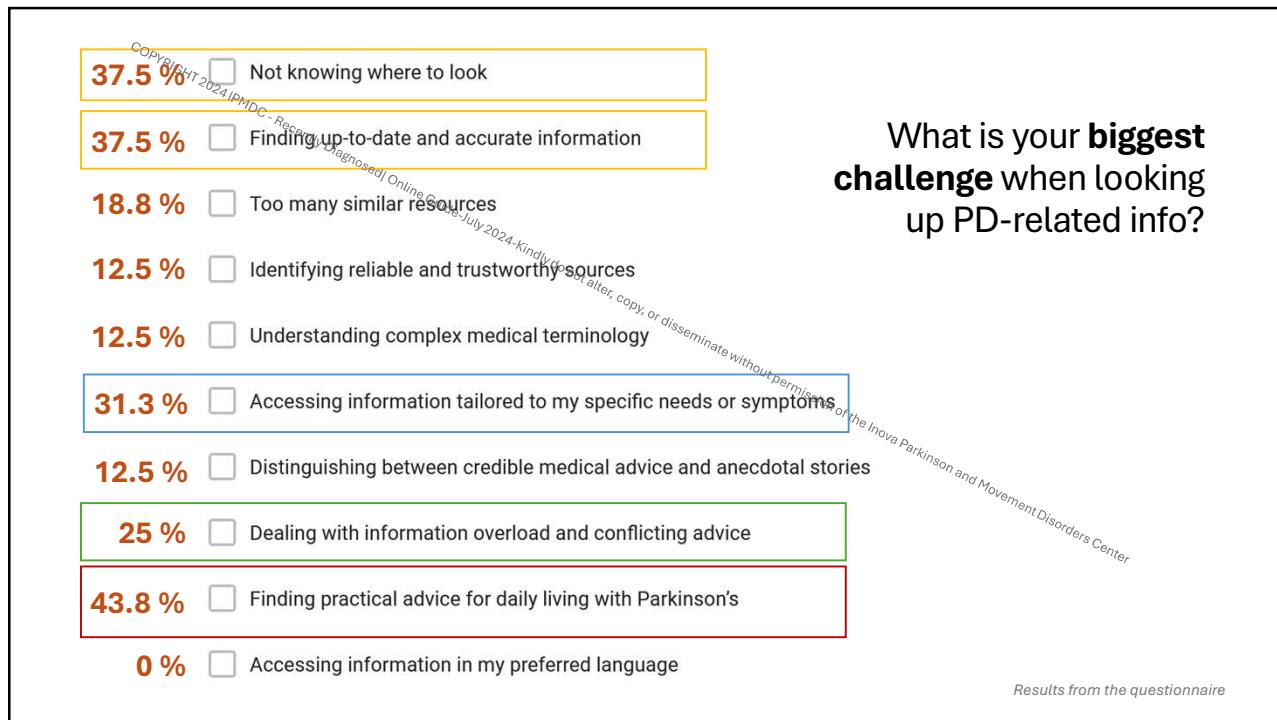
6



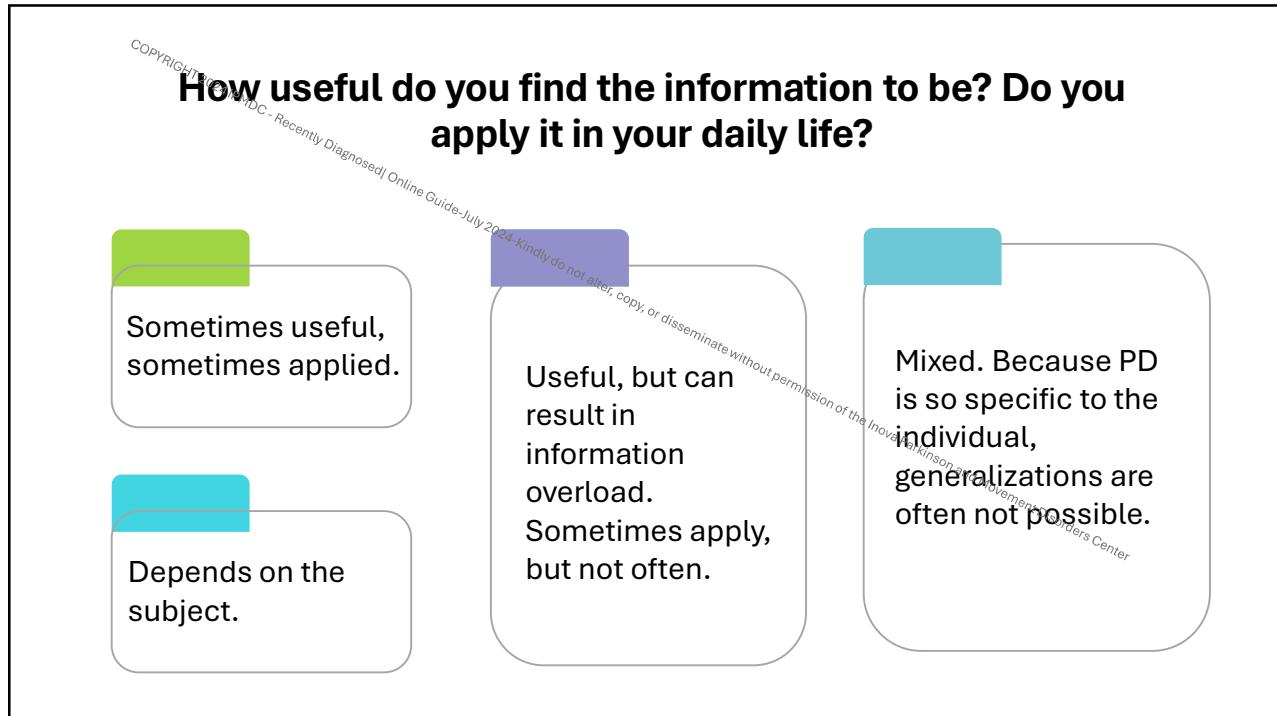
7



8



9

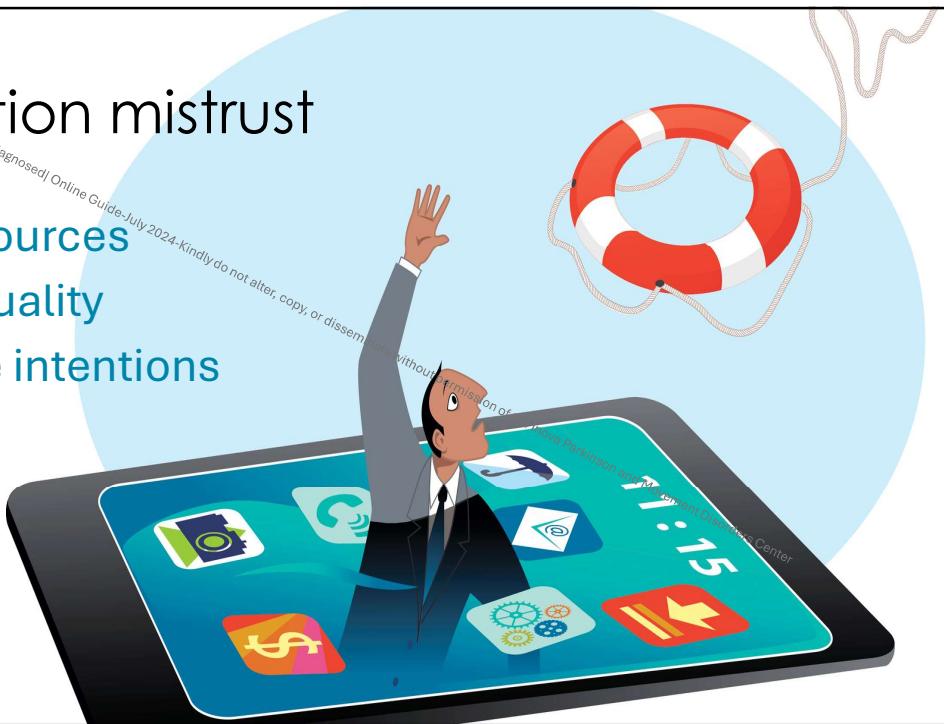


10

COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Ira M. Lampert Parkinson and Movement Disorders Center

Information mistrust

- Many resources
- Varying quality
- Less pure intentions

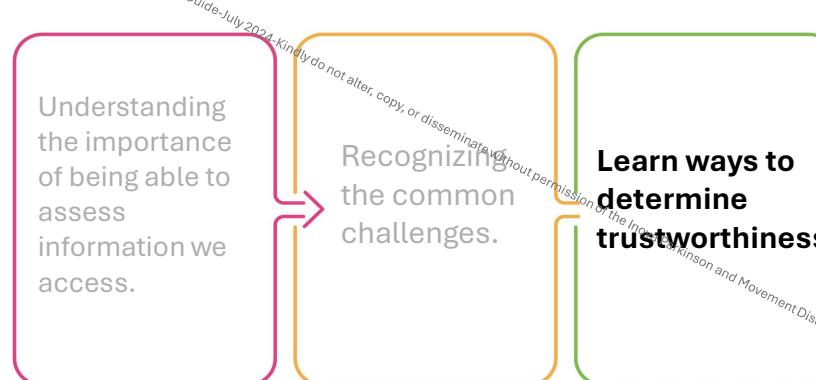


A cartoon illustration of a man in a suit and tie, wearing a life vest, drowning in a large smartphone. The phone's screen displays various app icons, including a camera, a gear, a dollar sign, and a gear with arrows. The man is reaching up from the phone's screen towards a red and white life preserver floating in the water above him. The background is a light blue circle representing water.

11

COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Ira M. Lampert Parkinson and Movement Disorders Center

OUR GOALS



Three goals are listed in colored boxes, connected by arrows:

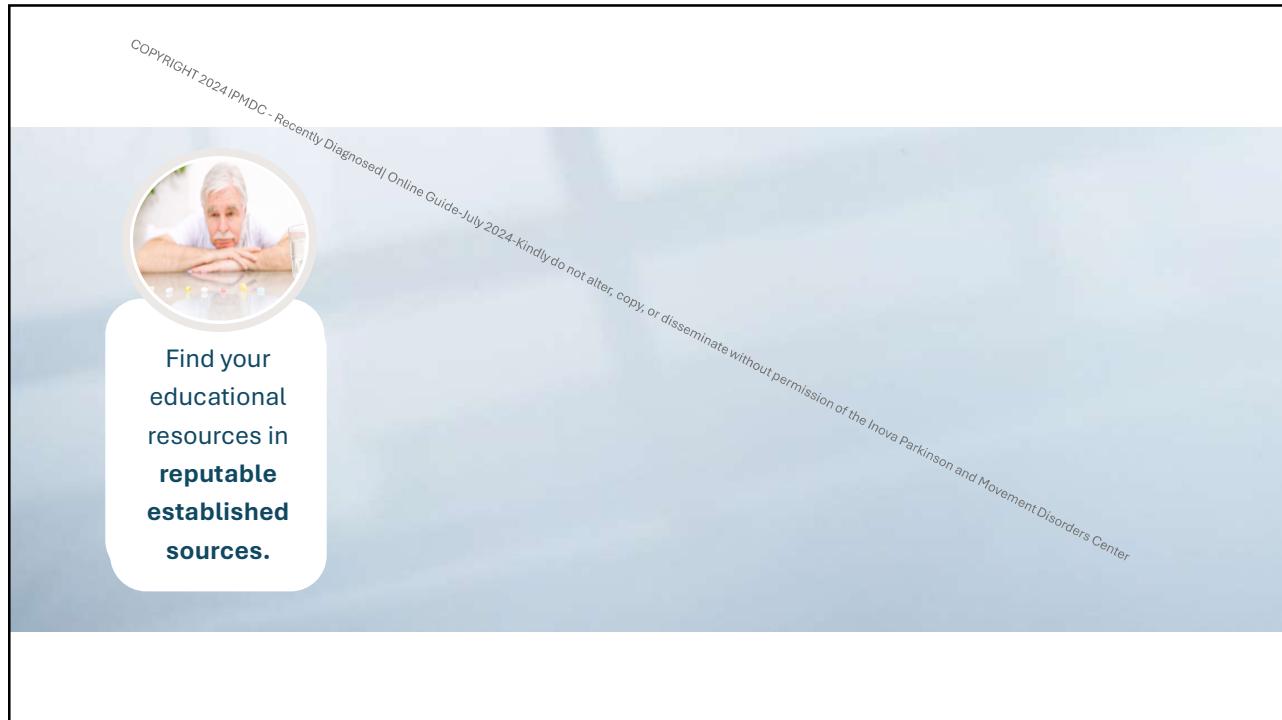
- Understanding the importance of being able to assess information we access.** (Pink box)
- Recognizing the common challenges.** (Orange box)
- Learn ways to determine trustworthiness** (Green box)

12



How do I know if the Parkinson's educational resources I use are trustworthy?

13



14

COPYRIGHT 2024 IPMDC - Recently Diagnosedj Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center



Medical societies

- International Parkinson and Movement Disorder Society (MDS) - <https://www.movementdisorders.org/>
- National Institutes of Health (NIH) - <https://www.nih.gov/>
- American Academy of Neurology (AAN) - <https://www.aan.com/>


International Parkinson and Movement Disorder Society


National Institutes of Health
Turning Discovery Into Health


AMERICAN ACADEMY OF
NEUROLOGY®

15

COPYRIGHT 2024 IPMDC - Recently Diagnosedj Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center



Prominent medical centers

- Muhammad Ali Parkinson's Center (MAPC)
- Mayo Clinic
- Cleveland Clinic
- Any other large center of repute...

16

COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Only| July 2024| Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center



Shop local

Your doctor's website

And their newsletter

[IPMDC.org](https://www.ipmdc.org)

[IPMDC News 7/8/2024](https://www.ipmdc.org/newsletter)

17

COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Only| July 2024| Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center



Non-profits

Esp. if you're looking for a certain voice or perspective

Parkinson's Foundation

THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

BRIAN GRANT FOUNDATION

DAVIS PHINNEY Foundation For Parkinson's every victory counts*

PMD Alliance
Parkinson & Movement Disorder Alliance

apda AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

World Parkinson Coalition

18

European and UK non-profits



COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Guide-July 2024-Kindly do not alter, copy or disseminate without permission of the Inova Parkinson and Movement Disorders Center

Parkinson's Europe*
<https://parkinsoneurope.org/>



Parkinson's UK
www.parkinsons.org.uk



COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Guide-July 2024-Kindly do not alter, copy or disseminate without permission of the Inova Parkinson and Movement Disorders Center

*Excellent resource for materials in other languages

19

Support groups



COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Guide-July 2024-Kindly do not alter, copy or disseminate without permission of the Inova Parkinson and Movement Disorders Center

- Optimal for recommendations for local resources
- Better groups will also keep on top of research and breakthroughs
- Recently diagnosed individuals might look for groups geared towards them

20



COPYRIGHT 2024 IPMDC - Recently Diagnosed Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center

Facebook groups



- Public and private groups on a range of topics
- Ability to post anonymously*

*CAVEAT – All activity is being tracked

21



COPYRIGHT 2024 IPMDC - Recently Diagnosed Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center

Online forums

- Smart Patients
- Health Unlocked
- Parkinson'sdisease.net
- Parkinson's Foundation
- Others....

22

COPYRIGHT 2024 IPMDC - Recently Diagnosed Online Guide-July 2024. You do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center

patientslikeme® Community for shared experiences

Prescription drugs		Over the counter drugs		Supplements	
Treatment	Patients	Treatment	Patients	Treatment	Patients
Duloxetine	72,386	Ibuprofen	21,833	Vitamin D	15,165
Pregabalin	51,672	Naproxen	21,132	Multivitamins	8,606
Gabapentin	50,000	Aspirin	13,390	Omega 3 Fish Oil	6,793
Prednisone	40,414	Acetaminophen (Paracetamol)	8,169	Vitamin D3 (colecalciferol)	5,715
Sertraline	37,058	Cetirizine	4,596	Calcium-Vitamin D	5,415
See all 2,712 prescription drugs		See all 664 over the counter drugs		See all 2,643 supplements	

Physical therapy		Equipment		Procedures	
Treatment	Patients	Treatment	Patients	Treatment	Patients
Physical Therapy	10,589	Walking Stick/Cane	11,084	Radiotherapy	5,710
Massage Therapy	2,630	Walker	6,187	MRI (magnetic resonance imaging)	3,229
Occupational Therapy	2,249	Therapeutic brace	5,133	Neuromuscular Electrical Stimulation	2,165
Speech / Language Therapy	1,941	Motorized scooter/chair	3,299	CT Scan (computerized tomography scan)	2,132
Pulmonary Rehabilitation	1,721	Wheelchair (manual)	3,100	Acupuncture	1,860
See all 159 physical therapies		See all 600 equipment		See all 729 procedures	

23

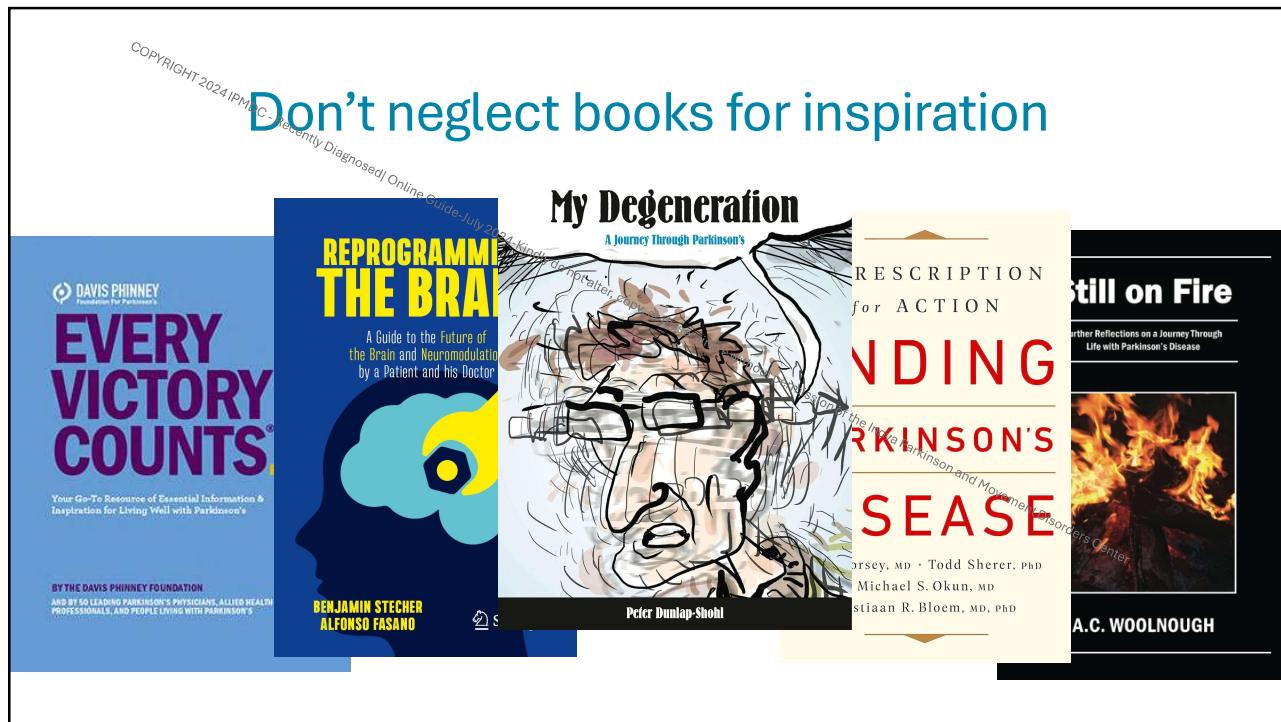
COPYRIGHT 2024 IPMDC - Recently Diagnosed Online Guide-July 2024. You do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center

ChatGPT

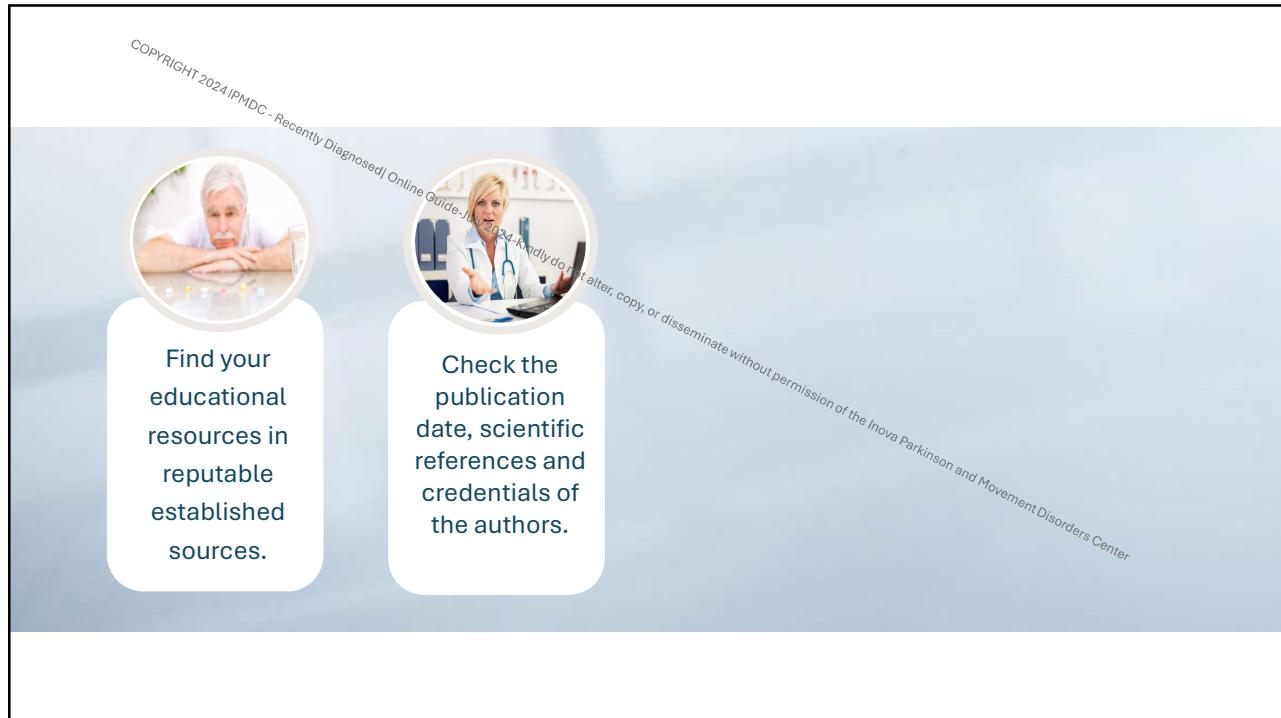
Probably not yet...

- Trained on a range of resources
 - including unreliable ones
 - “Hallucinations” are a known issue

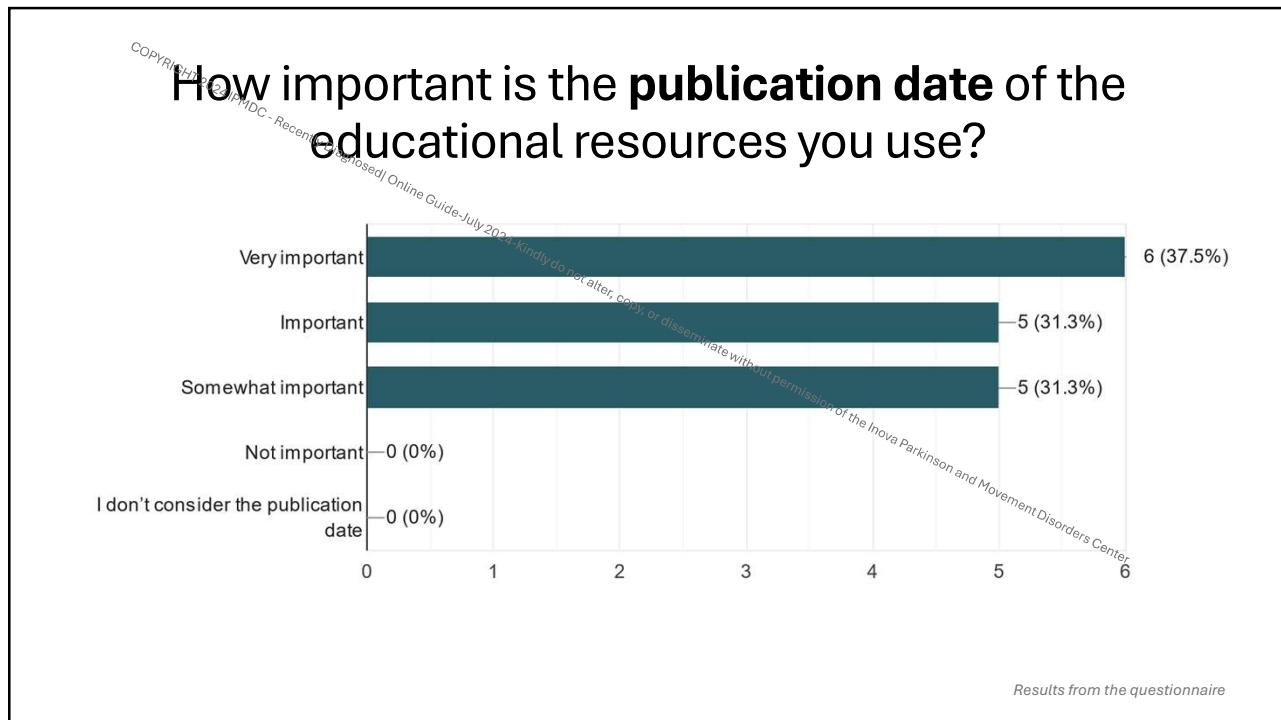
24



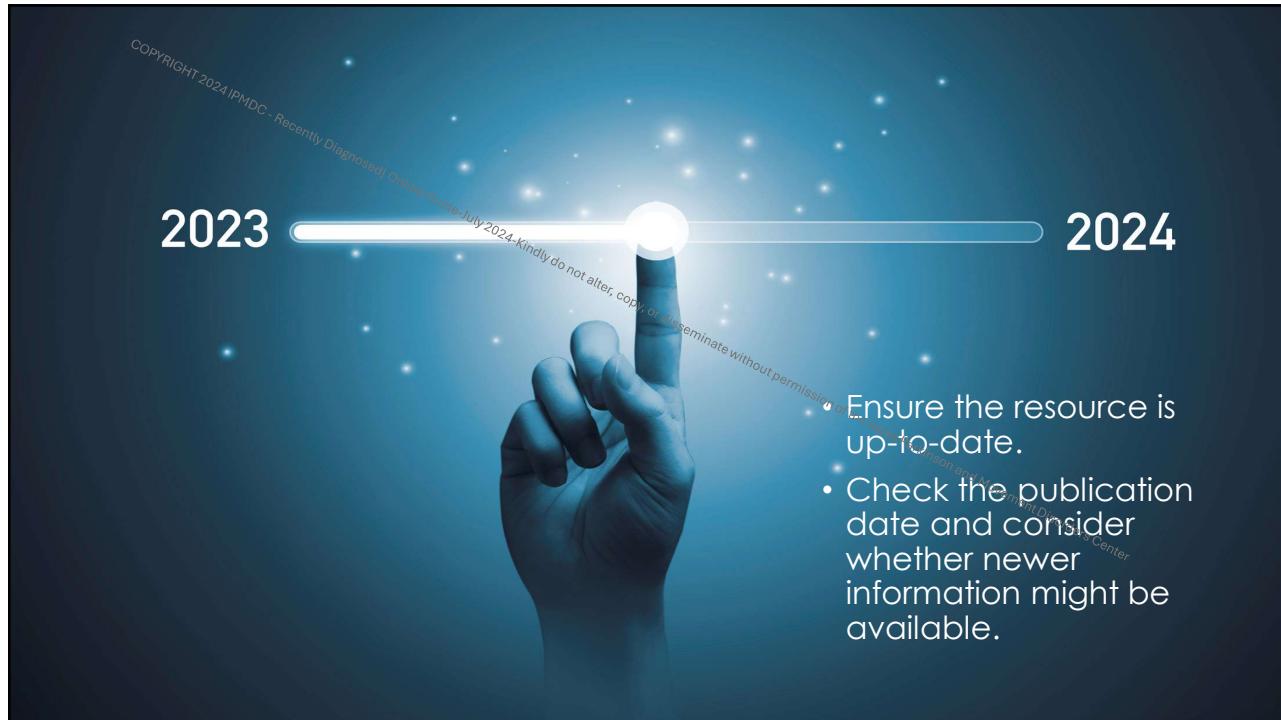
25



26



27



28

COPYRIGHT 2024 IPMDC - Recently Diagnosedj Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center

BEST BEFORE

Content has a shelf life

Depending on the topic

<3 years is best

<5 is OK

>5 may potentially be problematic

29

COPYRIGHT 2024 IPMDC - Recently Diagnosedj Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center

How frequently do you check if the educational content is supported by **scientific references and citations**?

Response	Count	Percentage
Always	0	0%
Often	7	43.8%
Sometimes	4	25%
Rarely	4	25%
Never	1	6.3%

Results from the questionnaire

30

Reliable educational resources cite their sources.

- Check the bibliography or reference list to see if the resource references credible and relevant sources.
- The presence of citations indicates thorough research and adds legitimacy to the content.

31

Do you verify the **credentials of the authors or creators of the educational content?**

Response	Count	Percentage
Always	0	0%
Often	2	12.5%
Sometimes	6	37.5%
Rarely	5	31.3%
Never	3	18.8%

COPYRIGHT 2024 IPMDC - Reliably diagnosed! Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center

Results from the questionnaire

32

COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Guide| July 2024| Kindly do not alter, copy, or disseminate without permission of the Innova Parkinson and Movement Disorders Center

Key questions:

- Are they experts in the field?
- Do they have relevant qualifications and experience?

DANCE for PD®
CLASSES | TRAINING | RESOURCES

LSVTBIG®

PWR!
Parkinson Wellness Recovery

SPEAK OUT!
Live with Intent

DUAL TASK FOR PARKINSON'S
Exercise to improve Movement, Voice & Cognition

OHIOHEALTH
DELAY THE DISEASE™

33

COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Guide| July 2024| Kindly do not alter, copy, or disseminate without permission of the Innova Parkinson and Movement Disorders Center

International Parkinson and Movement Disorder Society

International Parkinson and movement disorder Society (MDS) - <https://mds.movementdisorders.org/specialist-finder>

34

Red Flags

- Lacking/non-relevant professional credentials
- Not PD-specific or has multiple foci
- Selling supplements or cures and other unrelated products



35



Find your educational resources in reputable established sources.

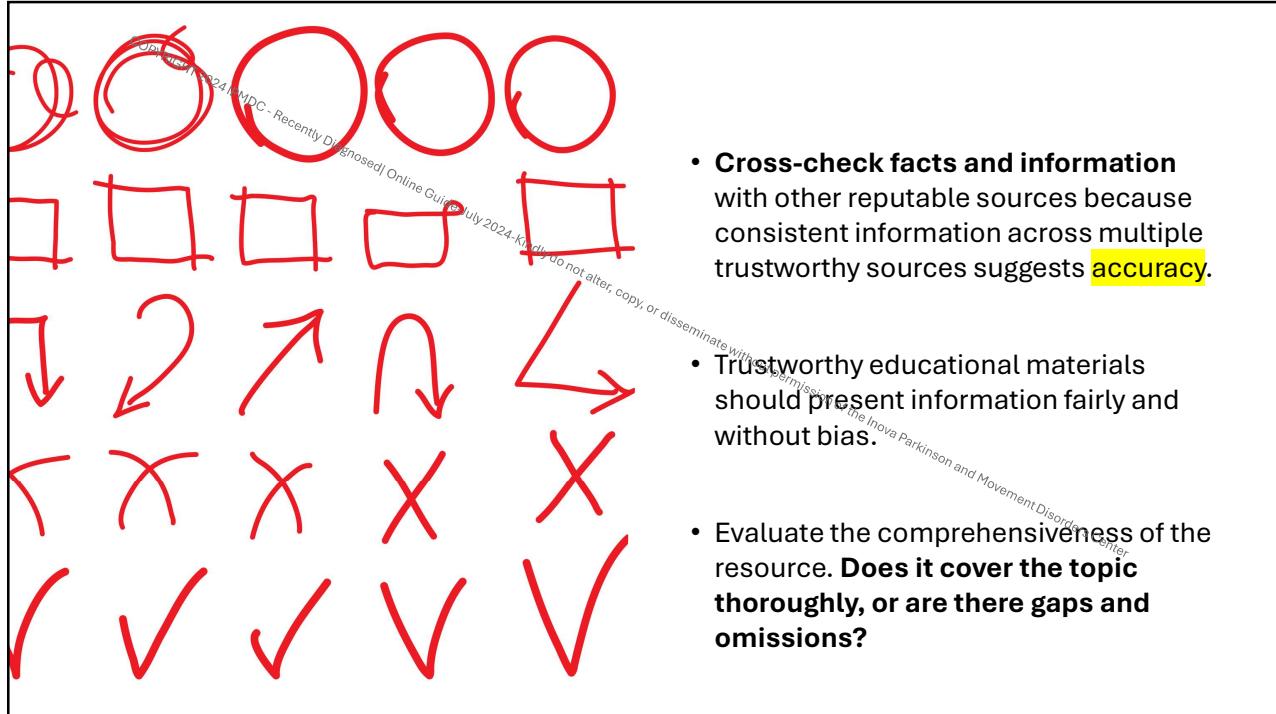


Check the publication date, scientific references and credentials of the authors.



Cross-check facts and information with other reputable sources

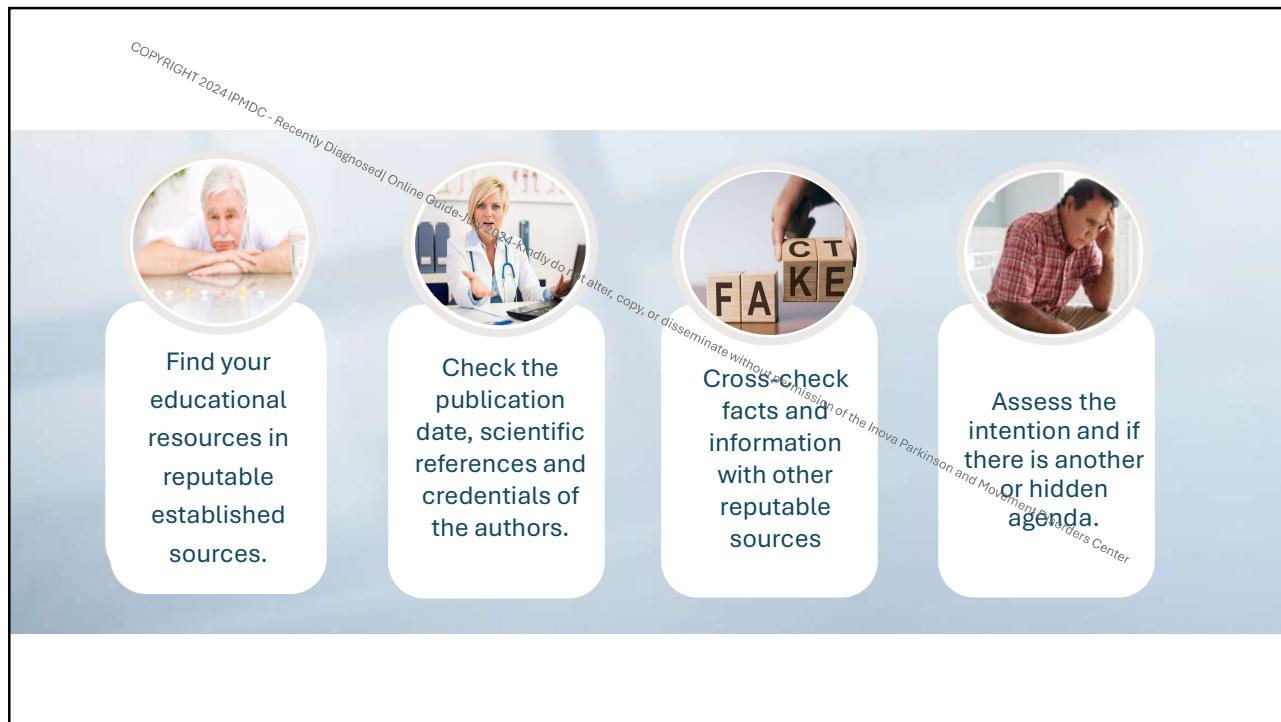
36



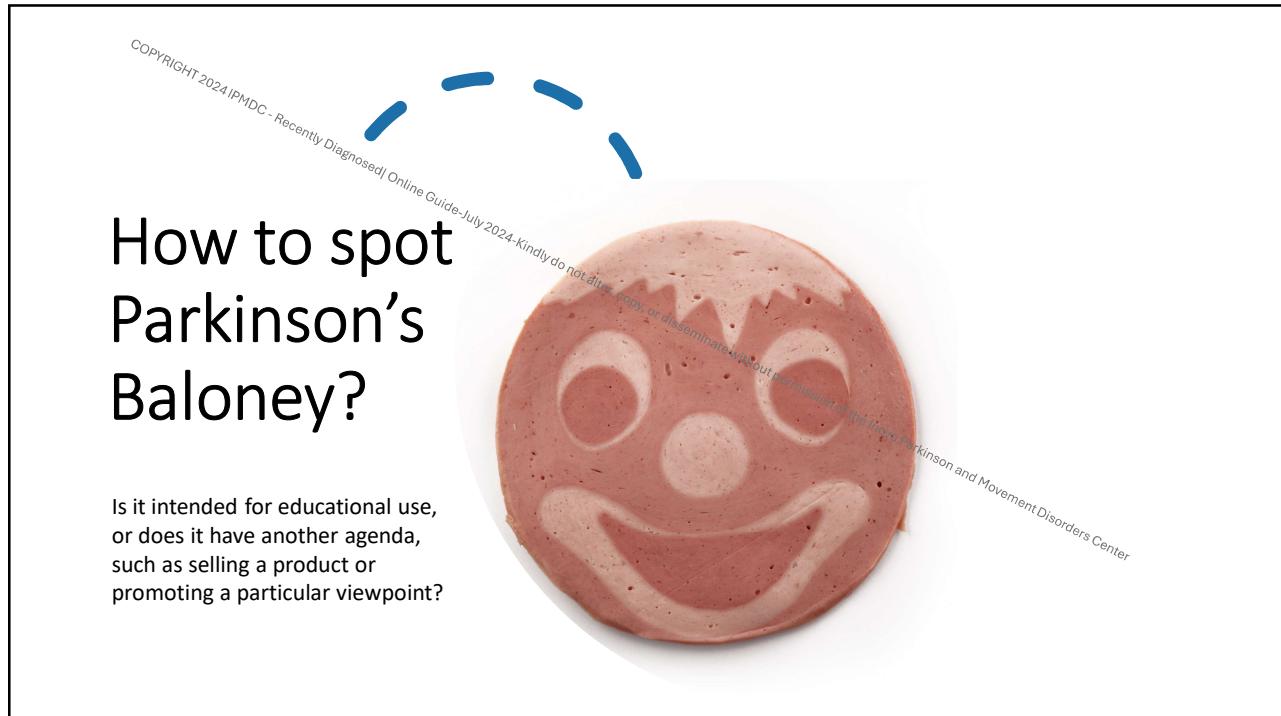
37



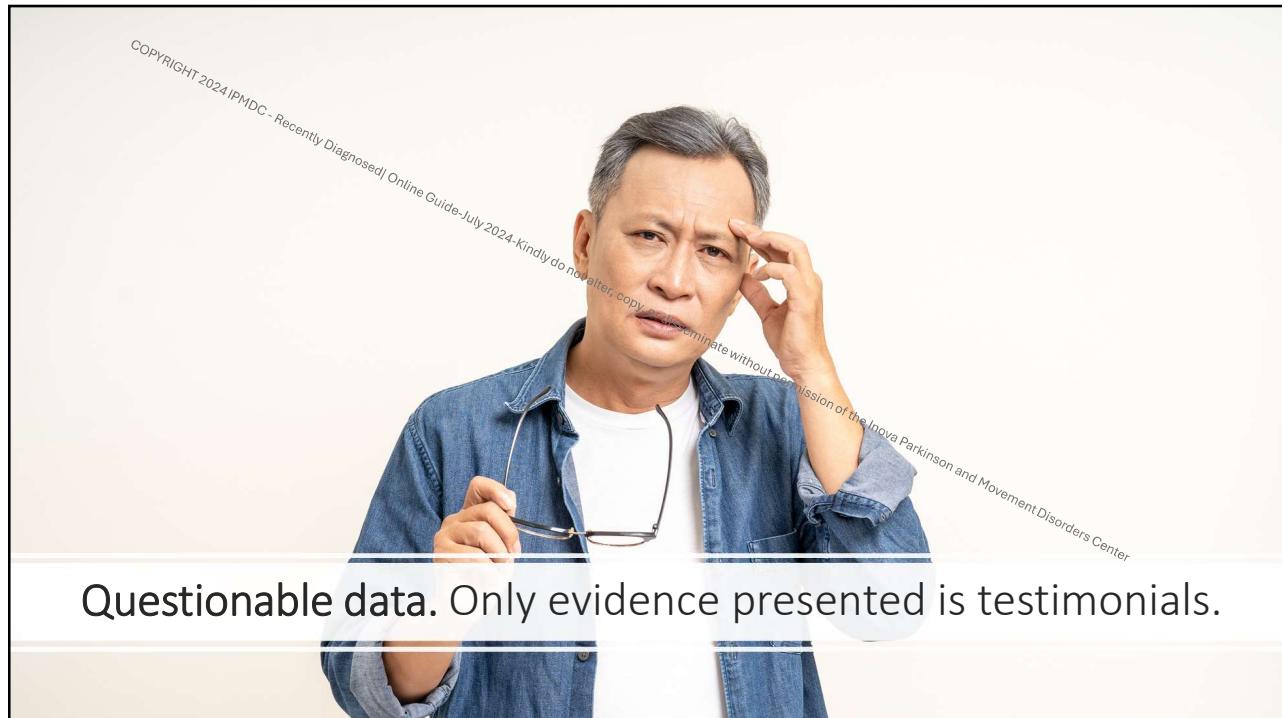
38



39



40



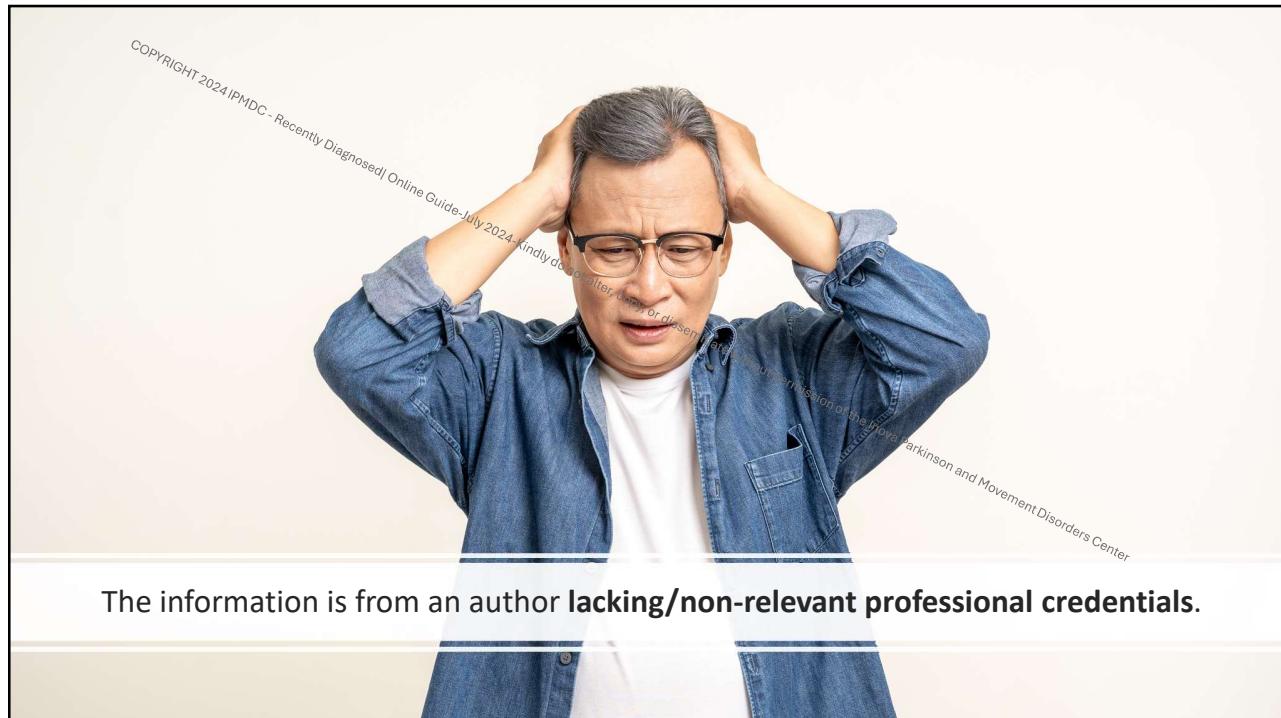
Questionable data. Only evidence presented is testimonials.

41



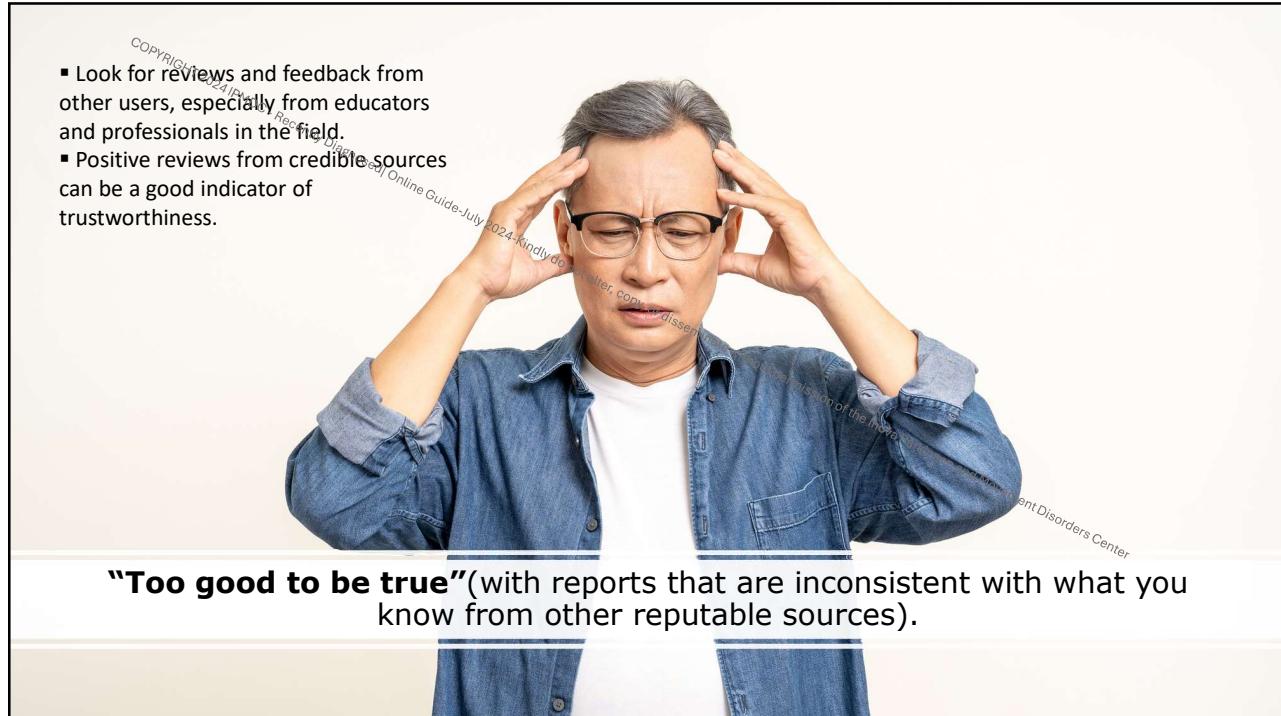
The information is tied to **selling products or cures or other miraculous products.**

42



The information is from an author **lacking/non-relevant professional credentials**.

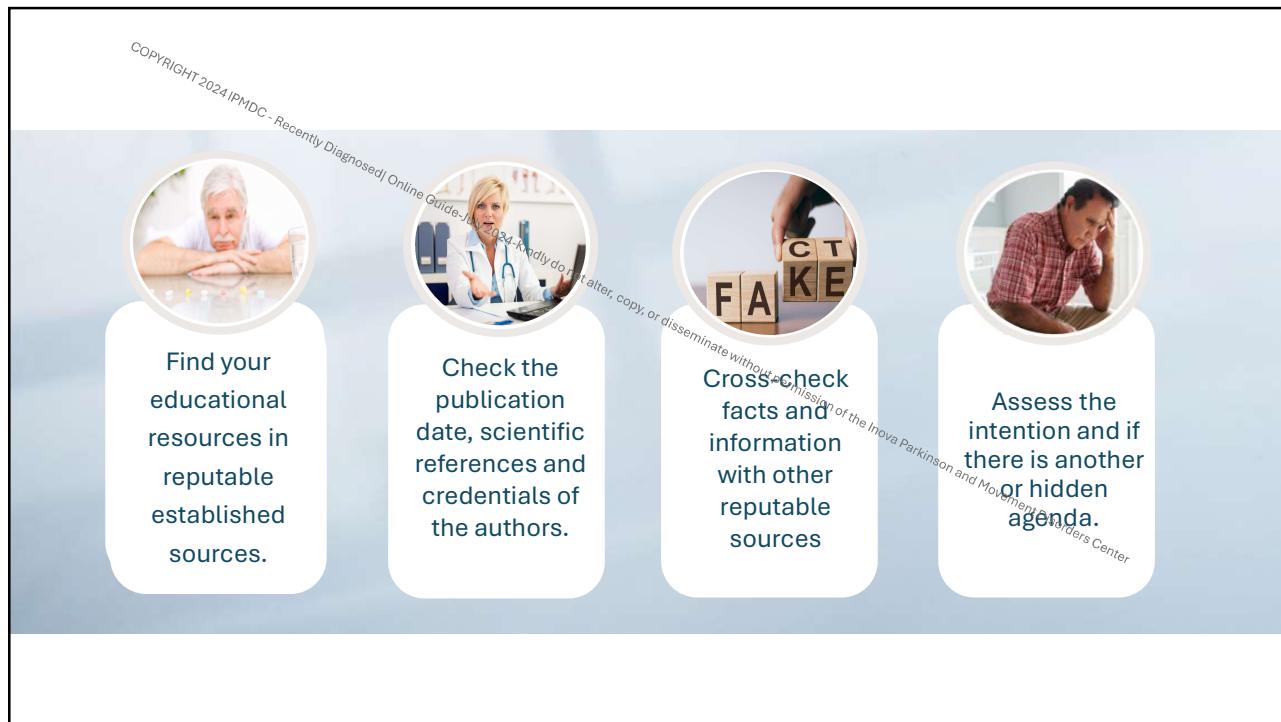
43



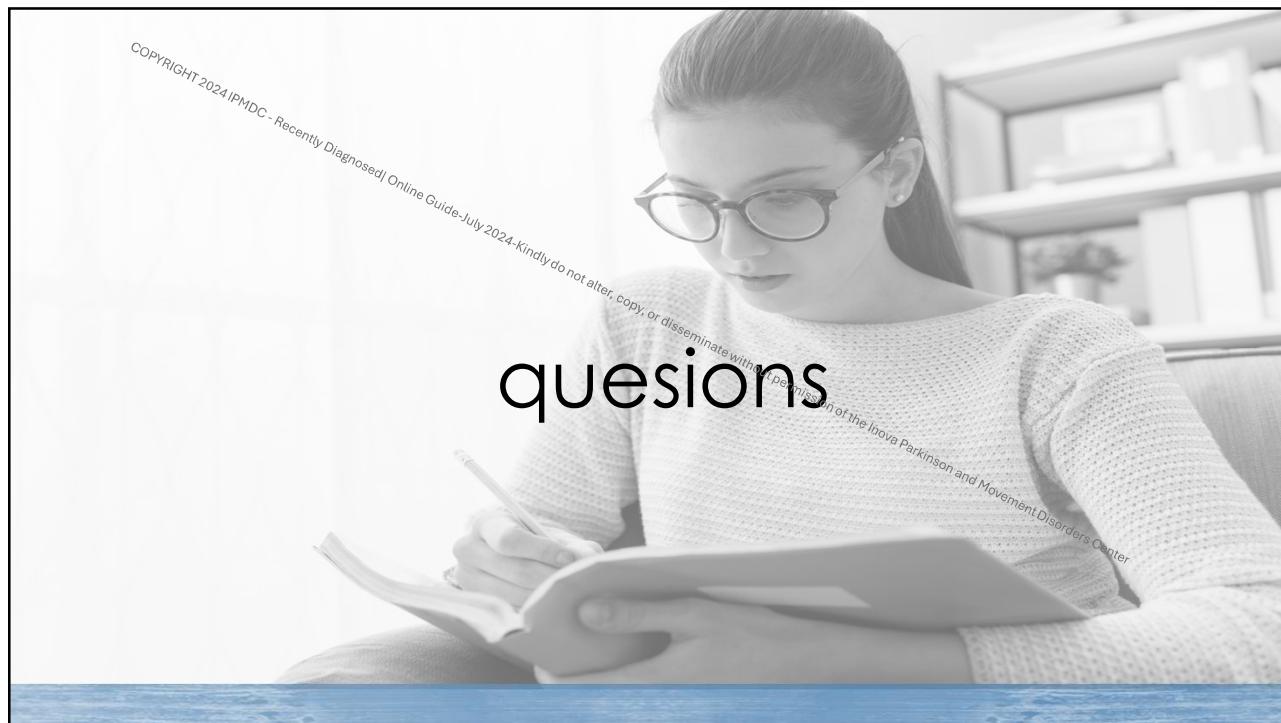
- Look for reviews and feedback from other users, especially from educators and professionals in the field.
- Positive reviews from credible sources can be a good indicator of trustworthiness.

“Too good to be true”(with reports that are inconsistent with what you know from other reputable sources).

44



45



46



47

COPYRIGHT 2024 IPMDC - Recently Diagnosed| Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Movement Disorders Center

Look for live programs so you can ask more personalized questions

For example, IPMDC programs like **“Let’s Chat About Thinking” series**

[« All Events](#)

Let’s Chat About Thinking series

Event Series: Let’s Chat About Thinking
July 10 from 2:30 pm - 3:30 pm EDT

with Dr. Jenn Paudural, Cognitive and Behavioral Neurologist

This month’s topic: **“I Don’t Have Any Memory Problems Anyway, Right, Honey?”**

Anosognosia is a phenomenon when the brain is unaware of the problems or challenges that it may be having. Other people may notice that we are forgetting or making more mistakes, but in our perspective, it seems like we are doing just fine! Why does this happen? Is it subconscious, or is it my brain stubbornly denying the truth? Sometimes trying to “prove who’s right” can lead to conflicts and defensiveness—and often this is the most troubling and sensitive part of having brain disease. Let’s talk about this sensitive topic of **not knowing what’s wrong** and decide if ignorance really is bliss.

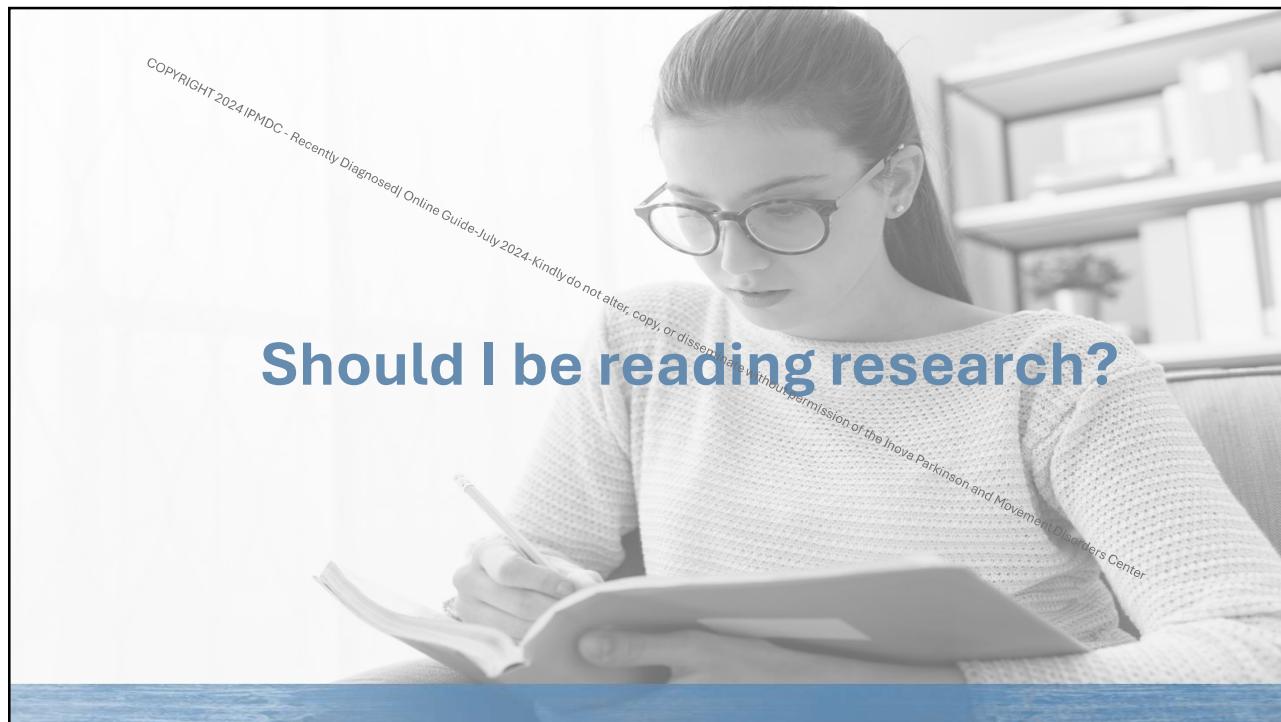


[Please click here to register](#)
and you'll receive your link to join in.

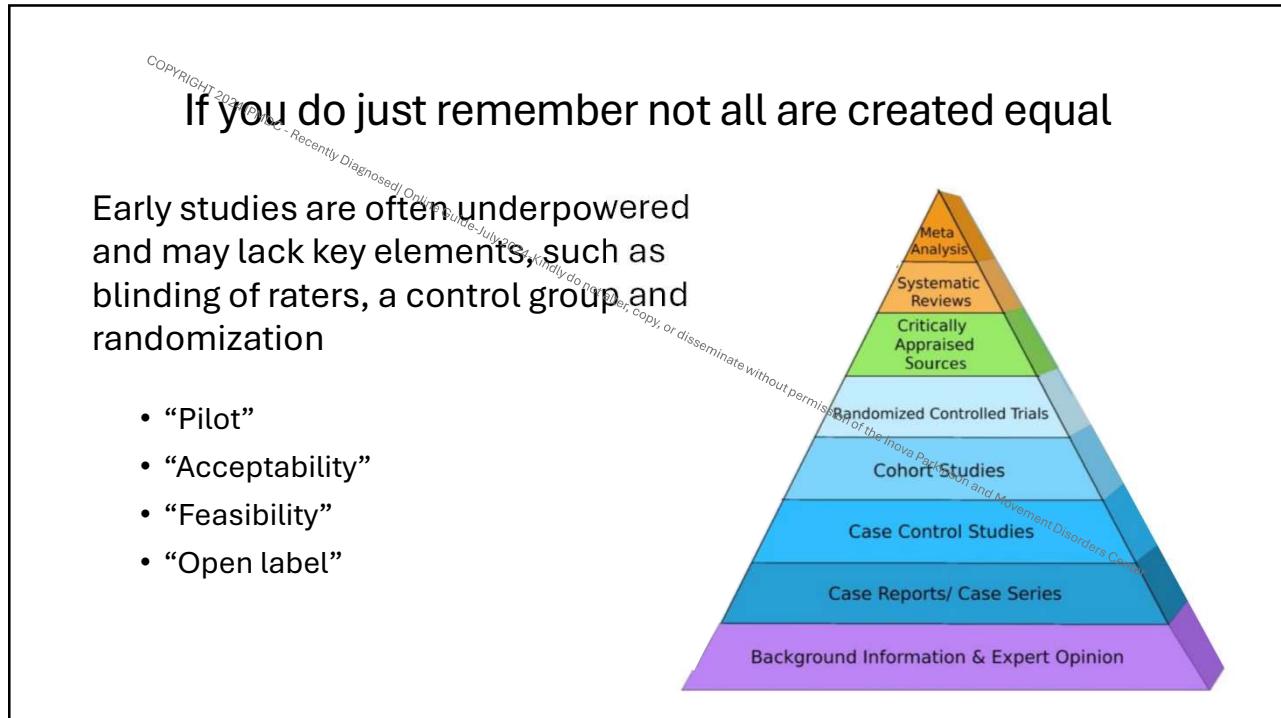


Jenn Paudural, MD
Cognitive and Behavioral Neurologist

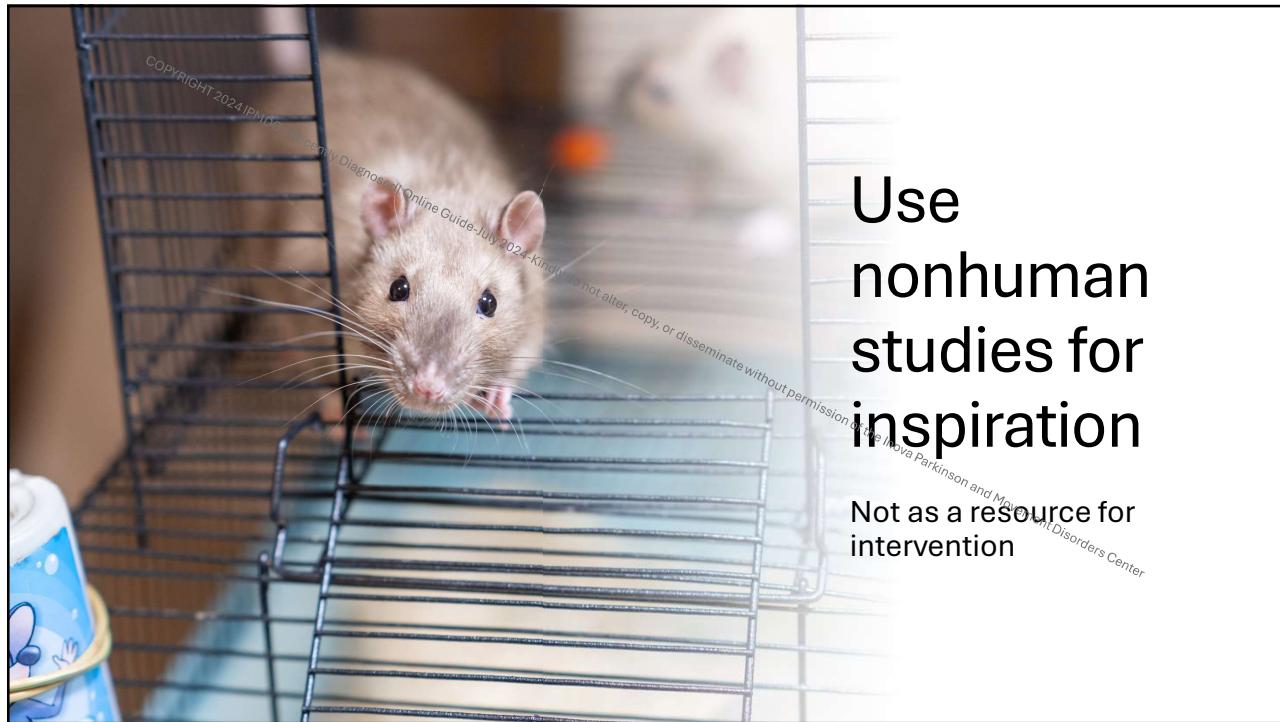
48



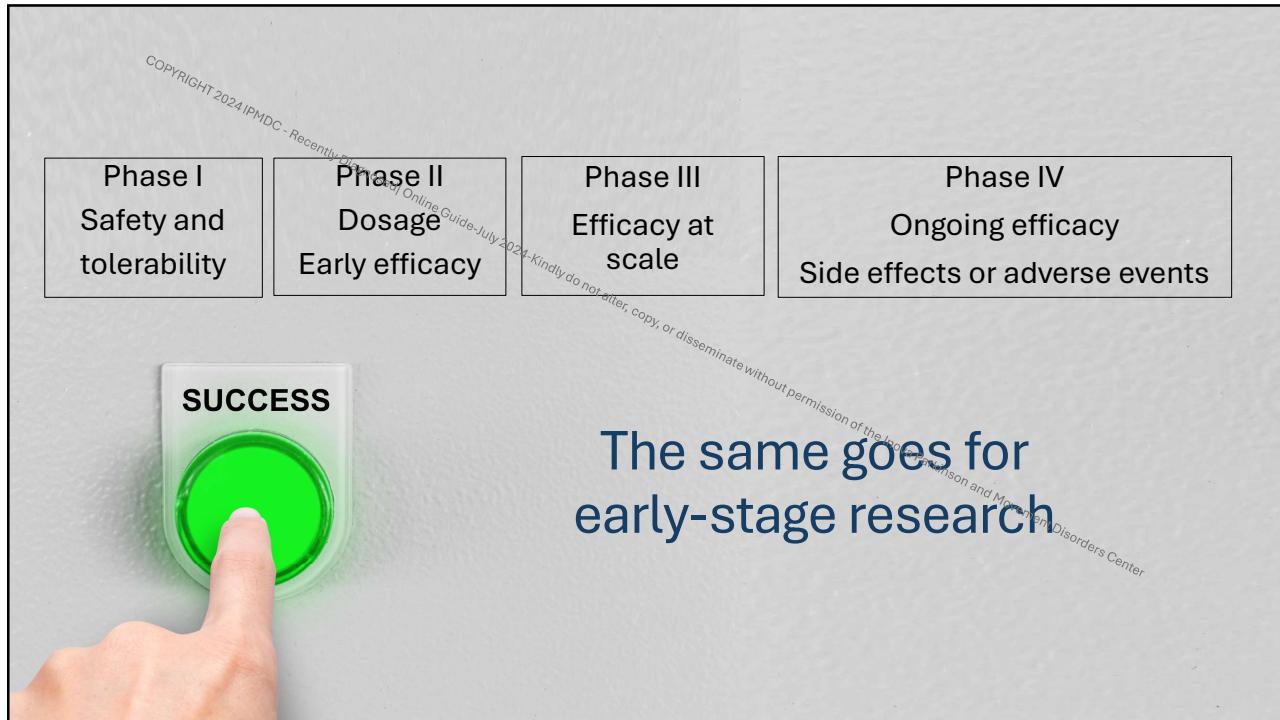
49



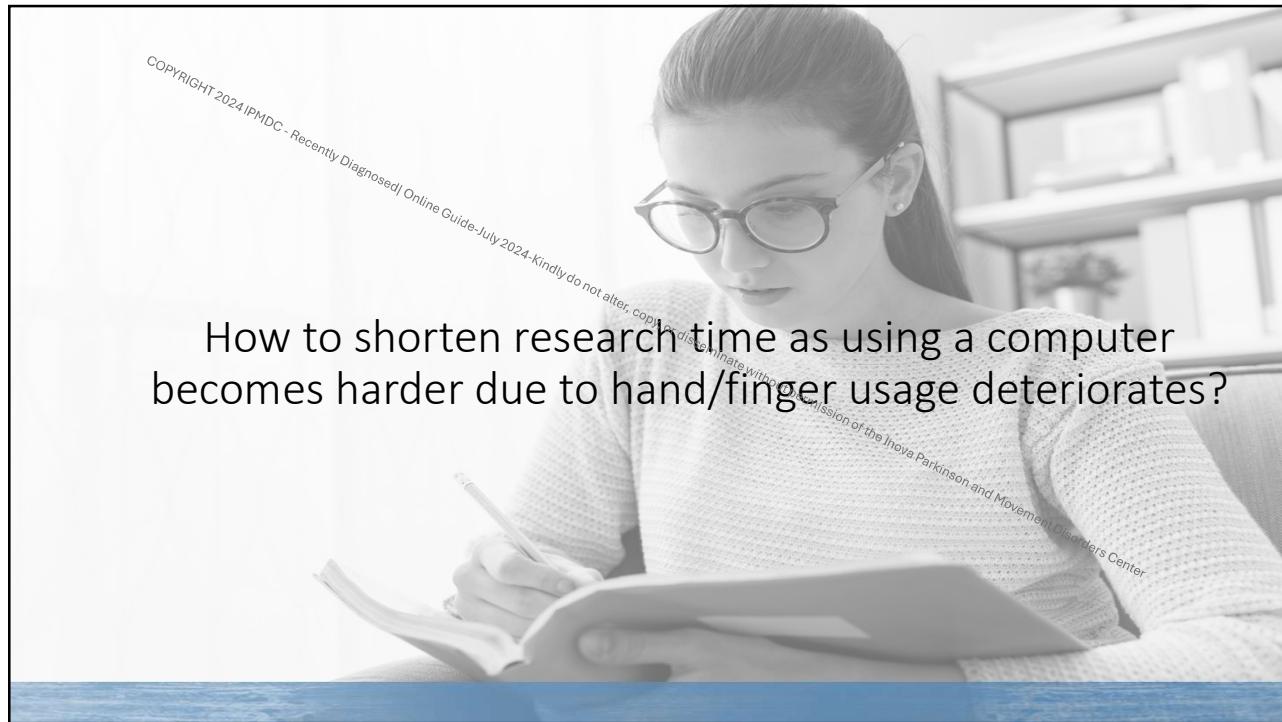
50



51



52



53

Google

Google alerts

Automated search results, delivered to your inbox...

Alerts

Monitor the web for interesting new content

Create an alert about...

My alerts (0)

COPYRIGHT 2024 IPMDC - Recently Diagnosedj Online Guide-July 2024-Kindly do not alter, copy, or disseminate without permission of the Jnova Parkinson and Movement Disorders Center

54

Consider “aggregators”



<https://parkinsonsnewstoday.com>



<https://www.sciencedaily.com>



<https://medicalxpress.com>



<https://www.news-medical.net>



<https://www.neurologylive.com>

55



Consider consulting a librarian

- Online searching
- Print resources
- Local organizations and groups

56

Summary

Systematically evaluating the educational resources you use for Parkinson's disease allows you to better determine their reliability and trustworthiness so that they can assist you more effectively.

57

Thank you for coming

58

29