

# Using Technology in your battle with Parkinson's

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Valencia Shores Parkinson's Group – Jan 2016



## **Goals for today's talk**

**Why do we need technology**

**What equipment do you need**

**Understanding types of information available**

**Examples**

**PD Resources in our area**



# Why do we need MORE Parkinson's information

## Better understanding of ourselves

- Caregivers know what to expect
- How to explain the disease to others

## Reminding ourselves of the “ons” and “offs” and what to do about them

## Everyone needs a support system when things don't go as expected

# Stranger danger

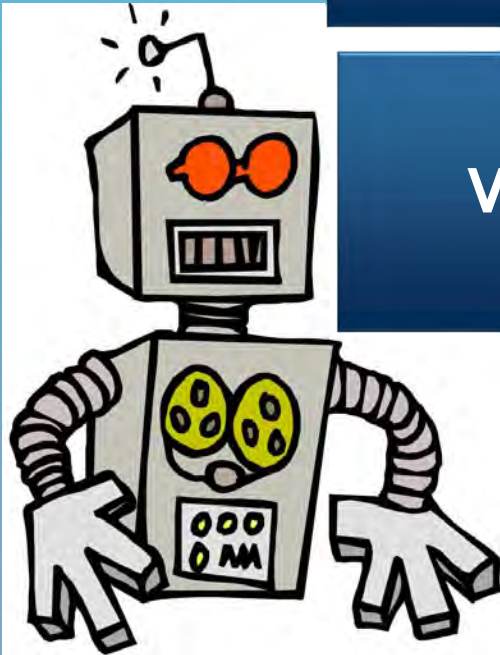
Quality of site

Quality of information

Viruses

Opinion versus Fact

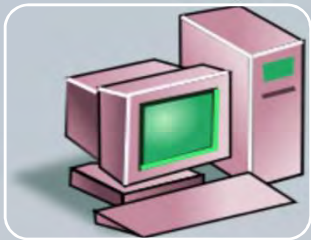
What works for someone else might not work for you



Do not download any software or open any email that doesn't look "right".  
Say NO to toolbars.  
Look for lock symbol.

# How to connect to the internet

## Hardware



Desktop  
Computer



Laptop  
Computer



Ipad or  
Tablet



Smart  
Phone

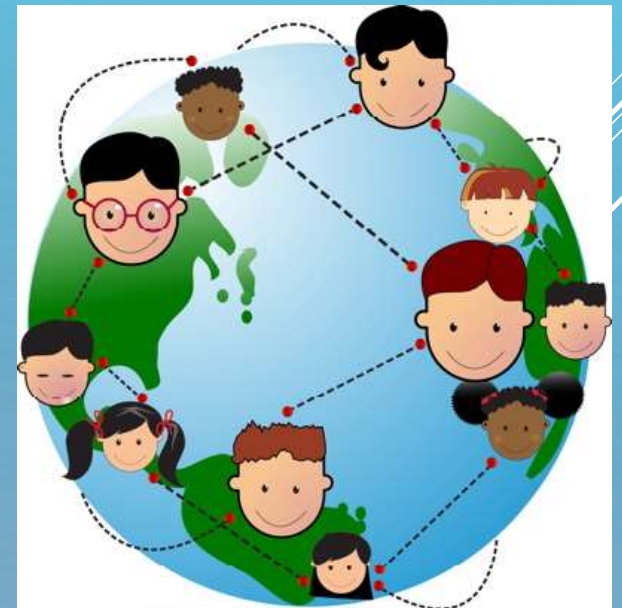


# How to connect to the internet

## Terminology

Wired versus  
Wireless

Wireless versus  
Cellular Data



Now that you are connected  
... where do we go?

## INFORMATION!!

Research

Sharing

- Live –webinars
- Bulletin Boards



# General Search

Internet Explorer

Google

Chrome

Safari

The screenshot shows a Yahoo! search results page for the query 'mirapex'. The search bar at the top contains 'mirapex' and a 'Search' button. Below the search bar, there are tabs for 'Web', 'Images', 'Video', 'Local', and 'Anytime'. The search results are displayed in a grid format. On the left side, there are four search results, each with a title, a URL, and a brief description. On the right side, there are four advertisements, each with a title, a URL, and a brief description. The search results include links to Drugs.com, WebMD, Wikipedia, and RxList. The advertisements include links to Rebates.com, Lifescript.com, HealthWarehouse.com, and GoodRx.com.

**YAHOO!** mirapex Search

**Web** Images Video Local Anytime

**Mirapex: Uses, Dosage & Side Effects - Drugs.com**  
[www.drugs.com/mirapex.html](http://www.drugs.com/mirapex.html) Cached  
Mirapex (pramipexole) treats the symptoms of Parkinson's disease and is also used to treat Restless Legs Syndrome. Includes **Mirapex** side effects, interactions and ...

<b>Mirapex Side Effects</b> Learn about the potential side effects of <b>Mirapex</b> ...	<b>Mirapex Drug Interactions</b> Show all medications in the database that may interact...
<b>Mirapex Dosage</b> Detailed <b>Mirapex</b> (pramipexole dihydrochloride) dosage...	<b>Drug Side Effects</b> Drug Side Effects. Please note - many side effects of...
<b>Restless Legs Syndrome</b> Drugs associated with Restless Legs Syndrome. The...	<b>Pramipexole</b> Only immediate-release pramipexole ( <b>Mirapex</b> ) is...

Search

**Mirapex oral : Uses, Side Effects, Interactions,...**  
[www.webmd.com/drugs/2/drug-3683/mirapex-oral/details](http://www.webmd.com/drugs/2/drug-3683/mirapex-oral/details) Cached  
Find patient medical information for **Mirapex oral** on WebMD including its uses, side effects and safety, interactions, pictures, warnings and user ratings.

**Pramipexole - Wikipedia, the free encyclopedia**  
[en.wikipedia.org/wiki/Pramipexole](http://en.wikipedia.org/wiki/Pramipexole) Cached  
Pramipexole (**Mirapex**, **Mirapexin**, **Sifrol**) is a dopamine agonist of the non-ergoline class indicated for treating Parkinson's disease (PD) and restless legs syndrome (RLS).

**Mirapex (Pramipexole) Drug Information:...**  
[www.rxlist.com](http://www.rxlist.com) › [home](#) › [drugs a-z list](#)  
Learn about the prescription medication **Mirapex** (Pramipexole), drug uses, dosage, side

**Ads**

**RX Savings**  
[www.Rebates.com](http://www.Rebates.com)  
Save Up to 75% At Your Pharmacy. Print or Text Free RX Discounts.

**Mirapex**  
[Lifescript.com/Health](http://Lifescript.com/Health)  
Find Facts, Symptoms & Treatments. Trusted By 50 Million Visitors.

**Buy Mirapex & Generics**  
[www.HealthWarehouse.com/Mirapex](http://www.HealthWarehouse.com/Mirapex)  
4.5 ★★★★★ rating for healthwarehouse.com  
FDA Approved Generic. US Licensed Pharmacy. Free Shipping Available!

**Relief From Restless Legs**  
[Ask.com/Relief From Restless Legs](http://Ask.com/Relief From Restless Legs)  
Relief From Restless Legs. Find Questions & Answers Now.

**Mirapex Price**  
[www.GoodRx.com](http://www.GoodRx.com)  
Get Your Instant Free Coupon Now. Save up to 80% on Prescriptions.

# www.webmd.com

## Research

General (basic) information

Symptom checker

Does not replace a call to your doctor

Gives worst case scenarios

Drugs

Pill identifier

The screenshot shows the WebMD website homepage. At the top left is the WebMD logo. To its right is a search bar with a magnifying glass icon. Further right are links for 'Sign In', 'Sign Up', and 'Subscribe'. Below the search bar is a navigation menu with categories: 'HEALTH A-Z', 'DRUGS & SUPPLEMENTS', 'LIVING HEALTHY', 'FAMILY & PREGNANCY', and 'NEWS & EXPERTS'. There are also social media icons for Facebook, Twitter, and Pinterest. The main content area is divided into three columns. The left column is titled 'Common Conditions' and lists various health issues like ADD/ADHD, Allergies, Arthritis, Cancer, Cold, Flu & Cough, Depression, Diabetes, Eye Health, Heart Disease, Heartburn/GERD, Pain Management, Sexual Conditions, Skin Problems, and Sleep Disorders. The middle column features a 'WebMDsymptomchecker' section with the heading 'Health concern on your mind?' and a 'Get Started' button. The right column is titled 'Resources' and includes links for 'Second Opinion', 'Communities', 'Insurance Guide', and 'Physician Directory'. At the bottom of the right column is a 'WebMD Pain Coach' section with an app icon and a description.

**WebMD** Search Sign In | Sign Up | Subscribe

[Symptoms](#) | [Doctors](#) | [Health Care Reform](#)

HEALTH A-Z ▾ DRUGS & SUPPLEMENTS ▾ LIVING HEALTHY ▾ FAMILY & PREGNANCY ▾ NEWS & EXPERTS ▾

**Common Conditions** [View All](#)

<a href="#">ADD/ADHD</a>	<a href="#">Eye Health</a>
<a href="#">Allergies</a>	<a href="#">Heart Disease</a>
<a href="#">Arthritis</a>	<a href="#">Heartburn/GERD</a>
<a href="#">Cancer</a>	<a href="#">Pain Management</a>
<a href="#">Cold, Flu &amp; Cough</a>	<a href="#">Sexual Conditions</a>
<a href="#">Depression</a>	<a href="#">Skin Problems</a>
<a href="#">Diabetes</a>	<a href="#">Sleep Disorders</a>

**Featured Topics**

- [See What Severe Psoriasis Looks Like](#)
- [16 Tips to Help You Get Organized](#)

**WebMDsymptomchecker**

**Health concern on your mind?**

See what your medical symptoms could mean, and learn about possible conditions.

[Get Started](#)

**Resources**

- Second Opinion:** Read expert perspectives on popular health topics.
- Communities:** Connect with people like you, and get expert guidance on living a healthy life.
- Insurance Guide:** Get ready for changes to your health care coverage.
- Physician Directory:** Find a doctor in your area.

**WebMD Pain Coach**

Track your pain levels, triggers, and treatments. Set goals and get tips with our app for iPhone.

# www.Parkinson.org

Research

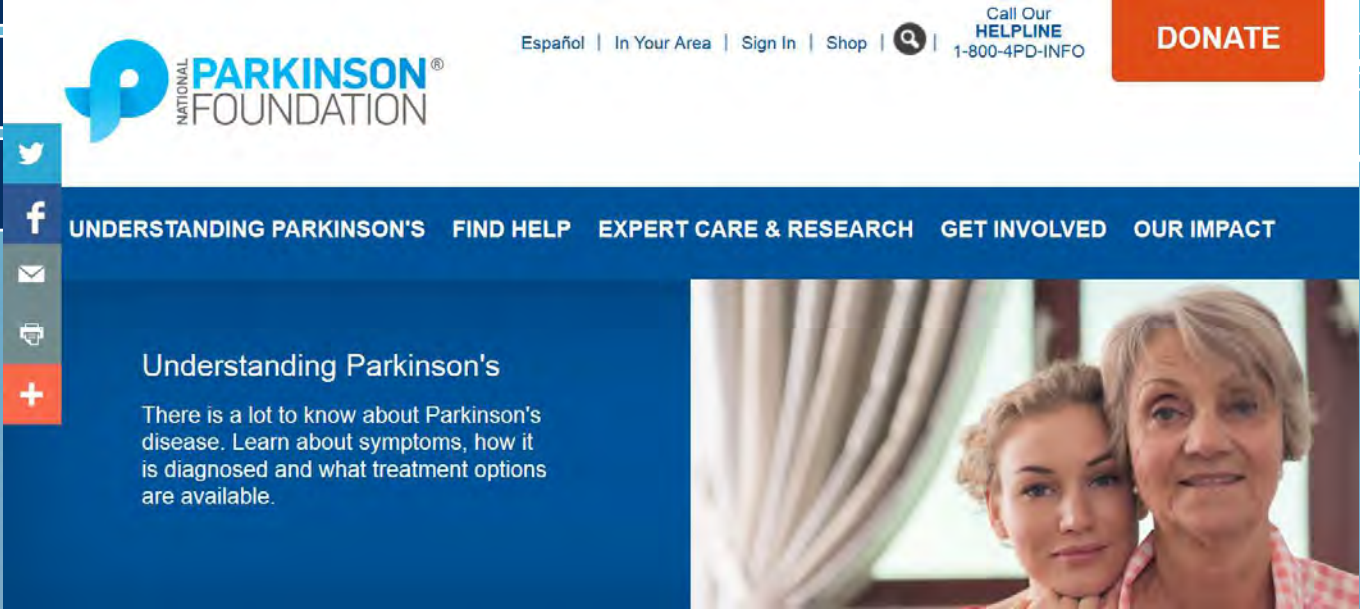
National Parkinson's Foundation (the group that is in Rochester)

PD educational materials, especially for newly diagnosed

Aware in Care

Research

Moving Day, etc.



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

Research

Parkinson Disease Foundation

More research oriented

Ask the Expert

Living with Parkinson's

Advocacy

The screenshot shows the Parkinson's Disease Foundation website. At the top left is the logo, a stylized yellow flower. To its right is the text "Parkinson's Disease Foundation". Further right are links for "Adjust Text Size: A | A | A", "En Español", a search bar with a "Search" button, and a green "DONATE NOW" button. Below this is a horizontal navigation menu with six items: "Funding Research & Results", "Understanding Parkinson's" (highlighted in yellow), "Living with Parkinson's", "Training Health Professionals", "Getting Involved", and "Supporting PDF". Below the menu are links for "Home", "Share Page", "Print Page", "Email Page", and social media icons for Facebook, Pinterest, Twitter, YouTube, and Email. The main content area features a featured article titled "Understanding Parkinson's" with a quote: "Staying informed about Parkinson's has helped me to 'live better' with the disease." - Lillian, 68, ten years after diagnosis. To the right of the article is a "PARKINSON'S HELPLINE" box with the phone number (800) 457-6676 and hours Monday through Friday, 9AM to 5 PM ET. Below the helpline is a "Learn More" button. At the bottom of the page, there is a paragraph: "Parkinson's disease is a **movement disorder** that is chronic and progressive, meaning that symptoms continue and worsen over time."

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

Research

Clinical Trials

Research

Understanding

Cutting Edge

Trial Finder

The screenshot displays the website's interface. At the top, the browser address bar shows the URL <https://www.michaeljfox.org/understanding-parkinsons/index.html?navid=understanding-pd>. The main header features the logo for 'THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH' and a search bar. A dark navigation bar contains the following menu items: 'OUR ROLE & IMPACT', 'BLOG', 'UNDERSTANDING PARKINSON'S', 'GET INVOLVED', and 'FOR RESEARCHERS'. A green 'DONATE' button is positioned on the right side of the header. The main content area is dominated by a large banner with a background image of a smiling cyclist. The banner text reads: 'ONLY OUR OPTIMISM IS INCURABLE.' Below this, it says: 'Find information and resources to help you stay positive and live well with Parkinson's disease.' To the right of the banner is a 'POPULAR TOPICS' sidebar with a list of links: 'Dyskinesia', 'Exercise and Parkinson's Disease', 'Parkinson's Disease Medications', and 'Sexual Health and Parkinson's'. A 'MORE' link with a right-pointing arrow is located at the bottom of the sidebar.

# Pharmaceutical Sites

## Research

[www.merck.com](http://www.merck.com)

[www.topix.com/com/teva](http://www.topix.com/com/teva)

<https://rytary.com/>

<http://www.azilect.com/>

- Remember – they can be biased for their product.
- Site usually goes away when generics are released

# 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.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



Showing Jul 14, 2015 - Oct 13, 2015



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

## SOCIAL / SHARING

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, the logo for the Parkinson's Foundation is visible, along with contact information: "Call Our HELPLINE 1-800-4PD-INFO" and a "DONATE" button. Navigation tabs for "Forums" and "Members" are present, along with a "View New Content" link. Below the navigation, there are buttons for "Sign Up For Our E-NEWSLETTER" and "Like us on FACEBOOK". The main heading is "Ask The Surgical Team", followed by a disclaimer: "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." Below this, there is a section for "Frequently Asked Questions - Step by step guides" posted by Forum Admin. A "Subforums" section lists "Archive - 2011 Posts of the Week" with 16 topics and 17 replies, and a "Post of the Week: Why do pe..." by Dr. Okun from 12 Dec 2011. A pagination bar shows "Page 1 of 17" with "NEXT" and "Previous" buttons. A "Recently Updated" section lists three pinned posts:

Post Title	Replies	Views	Author	Date
<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 Jun 2012	11 replies	2,389 views	Dr. Okun	27 Feb 2015

**www.Facebook.com**

## SOCIAL / SHARING

**NOT RECOMENDED**

**Must watch security settings**

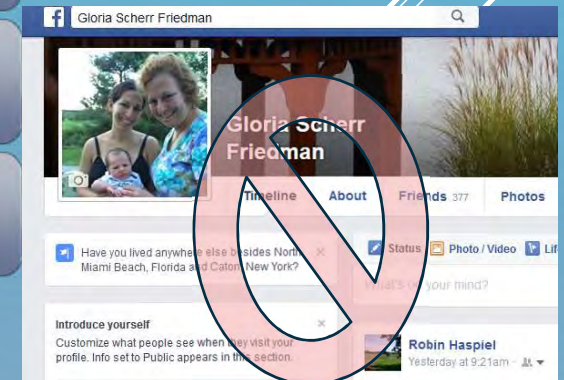
**Do you really want to mix PD acquaintances with friends and family.**

**It's ok to use Facebook login at another site as long a you read their rules about data sharing, but better to use a unique login**

**Information less factual**

**Less likely to be moderated, although there are closed groups where you have to ask a self appointed administrator to join their group.**

**If you do use this, make sure your PD friends are in a separate friend group.**



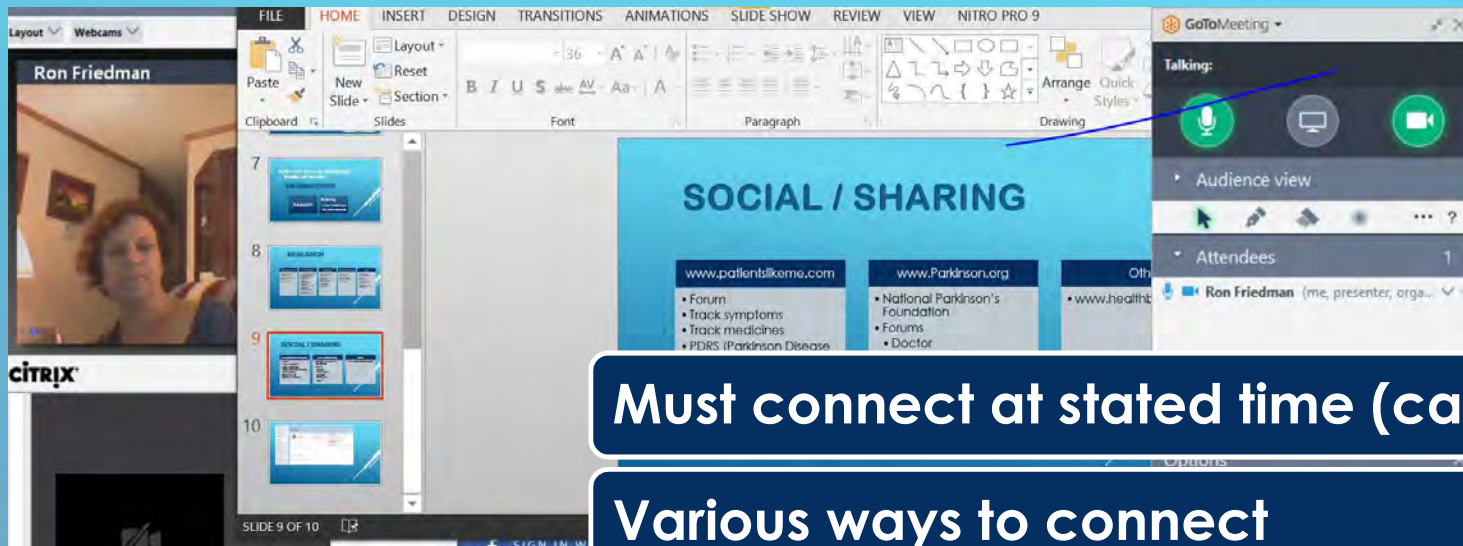
# Other sites

**SOCIAL / SHARING**

[www.healthboards.com](http://www.healthboards.com)

[www.myparkinsonsteam.com](http://www.myparkinsonsteam.com)

# LIVE WEBINARS



**Must connect at stated time (can usually join late)**

**Various ways to connect**

**Listen only or live participation**

**Phone or computer speakers and microphone**

**Might not be available on phone or tablet**

# RECORDED WEBINARS

Can watch anytime

Information only

No feedback, no Q&A

Might go to download directory

Plays *with media player or YouTube*

Need speaker or headset to hear narration



Note: This video will play if you click on it but there is no sound.

# Palm Beach County Resources

## National Parkinson Foundation of South Palm Beach

- <http://www.npfsouthpalmbeach.org/>
- 21301 Powerline Rd, Ste 300 in Boca Raton
- [contact@npfsouthpalmbeach.org](mailto:contact@npfsouthpalmbeach.org)

Moving Day

Cleveland Clinic West Palm Parkinson's and Movement Disorders

Palm Beach Neuroscience Institute

- <http://www.pbni.com/parkinsons-disease>

# National Parkinson Foundation South Palm Beach

**Research**

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

Moving Day



## Calendar

Sun	Mon	Tue	Wed	Thu	Fri	Sat
					1 Surf and Turf Boynton Beach 10:00 am Yoga and Tai Chi for PD 11:00 am Jupiter Lunch Out 12:30 pm	2 Qigong and Tai Chi at Rutherford Park 10:00 am
3	4 Boynton Beach Care-partners Support Group 10:00 am Surf and Turf Boynton Beach 10:00 am	5 Tai Chi and Qigong with Jennifer Yu 10:00 am Surf and Turf Boca Raton 11:30 am	6 Surf and Turf Boynton Beach 10:00 am Vocal Enhancement 10:30 am	7 Surf and Turf Boca Raton 11:30 am	8 Surf and Turf Boynton Beach 10:00 am Yoga and Tai Chi for PD 11:00 am	9 Qigong and Tai Chi at Rutherford Park 10:00 am
10	11 Boynton Beach Care-partners Support Group 10:00 am Surf and Turf Boynton Beach 10:00 am	12 Tai Chi and Qigong with Jennifer Yu 10:00 am Surf and Turf Boca Raton 11:30 am	13 Surf and Turf Boynton Beach 10:00 am Vocal Enhancement 10:30 am	14 Surf and Turf Boca Raton 11:30 am	15 Surf and Turf Boynton Beach 10:00 am Yoga and Tai Chi for PD 11:00 am Jupiter Support Group 12:30 pm	16 Qigong and Tai Chi at Rutherford Park 10:00 am

<http://my.clevelandclinic.org/florida/departments/neurosciences/parkinsons-movement-disorders>

## Parkinson's Disease: An Overview

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- ▶ Parkinson's Disease: An Overview
  - ▶ Counseling and Parkinson's Disease
  - ▶ Exercise for People with Parkinson's Disease
  - ▶ Living with Parkinson's Disease: Sleep Problems
  - ▶ Medications for Parkinson's Disease
  - ▶ Parkinson's Disease: Preventing Falls & Maintaining Balance
  - ▶ Speech Therapy for Parkinson's Disease
  - ▶ Depression: Overview and Its Role in Parkinson's Disease
  - ▶ Parkinson's Disease: Symptoms
  - ▶ Caregiving: Preparing Your Home
  - ▶ Parkinson's Disease Resources
  - ▶ Tips for Caregivers
-



# Palm Beach Neuroscience Institute

Research

<http://www.pbni.com/parkinsons-disease>



SOUTH FLORIDA'S COMPREHENSIVE NEUROSCIENCE CENTER

# QUESTIONS / DISCUSSION

