If you care for someone who has Parkinson’s disease, you are not alone.
Who’s here?

In Portland, OR:
• 150+ registrants
  – 24 states
  – 4 countries

Online:
• 750+ registrants
  – 49 states, DC, Puerto Rico
  – 15 countries
You are doing a great job!
Research Helps Set NPF Apart

• “…research from NPF showed better care could prevent the death of almost 7,000 annually…”
  Fast Company

• “According to a study by NPF, more than half suffer from clinical depression, part of the disease process…”
  Forbes

• “In a 2012 study by the National Parkinson Foundation, 61 percent of 5,557 Parkinson’s patients suffered from depression…”
  Washington Post
What’s Going on in Caregiving?

“Let’s look at the data!”*

- There is high prevalence of caregiver burden in PD. (Surprised??)
- PDQ-39 total score is the strongest predictor of caregiver burden.
- Other predictors of severe caregiver burden include longer disease duration, disease severity, and more “on-off” fluctuations.

*NPF’s Parkinson’s Outcomes Project is the largest-ever clinical study of Parkinson’s, with almost 10,000 people with PD enrolled, along with their caregivers.
What’s Going on in Caregiving?

“Let’s look at the data!”*

- A change in caregiver can impact the health of both the person with Parkinson’s AND the caregiver.
- Caregiver transition (from spouse to other relative, paid caregiver, or other) is associated with worsening of clinical outcomes and health-related quality of life.
- Caregiver strain is a particular consideration for the family caregiver newly introduced to Parkinson’s care.
NPF’s Resources and Services Set Us Apart

Staffed by PD information specialists from various allied health professions, our Helpline* is here to support you in any possible way.

Anna Hedges, MSW  Paula Wiener, LCSW  Dianett Ojeda, RN  Sharon Metz, RN  Adolfo Diaz, BSBA, PTA

*The NPF Helpline has responded to more than 60,000 cases since it launched in 2010.
What’s Going on in Caregiving?

HELPLINE: English / Español
1.800.4PD.INFO (473-4636)
Get your PD questions answered.

Should I tell the doctor about this?

My husband insists I’m cheating on him, I don’t know what to do.

I need a break. Where can I get help?
My mom does not want to do the things she used to love. How do I motivate her?
Integrated Mission Delivery
Centers of Excellence, Parkinson’s Outcomes Project, research, Allied Team Training for Parkinson’s

People affected by Parkinson’s

Helpline, chapters, field staff

Education, publications, Aware in Care online, etc.
Caring and Coping

Look in your bags!
- Tip sheets
- Worksheets
- CareMAP videos
- Caregiver stories

For webcast and video viewers: order your free copy at www.parkinson.org/books or by contacting the NPF Helpline at 1-800-4PD-INFO or helpline@parkinson.org.
CareMAP

- Comprehensive guide for caregivers of people with advanced-stage Parkinson’s
  - But includes helpful tips for ALL stages!
- Website launched in Nov. 2014 for National Family Caregivers Month
- Developed with expert advisors:
  - Rose Wichmann, PT, and Joan Gardner, RN, BSN, Struther’s Parkinson’s Center
  - Dan Davis, NPF Ohio
  - Lennore Bevis, caregiver
CareMAP

40 how-to videos and caregiver stories provide practical and personal tips on:

- Changes around the house
- Plans and scheduling
- Movement and falls
- Dressing
- Bathroom
- Mealtime and swallowing
- Medications and general health
- Thinking and behavior changes
- Activities at home
- Travel and Transportation
- Rest and sleep
- Getting outside help
- Caring from afar
- Planning ahead
- Caring for YOU, the caregiver

www.caremap.parkinson.org
CareMAP

¡Disponible en español!

- Ayudando a una persona con la enfermedad de Parkinson
- Cambios para realizar en casa
- Planear y fijar horarios
- Movimientos y caídas
- El vestirse
- La alimentación y la deglución
- El baño
- Cambios en el pensamiento y el comportamiento
- Medicamentos y la salud en general
- Las actividades en casa
- Los viajes y el transporte
- El descanso y el sueño
Your Caregiving Toolbox

There is no one-size-fits-all approach to taking care of someone with Parkinson’s.

Parkinson.org/forums
The Best Tool for Family Caregivers?

(each other)