The advent of the smart phone was small in comparison to what has come afterward. The self-driving car, Siri and Alexa – computers that listen and respond to our every command – are real, no longer sci-fi concepts.

One of the most exciting fields of technological development is that of healthcare applications (apps), to make taking care of yourself, communicating with your provider, and learning about upcoming treatments much easier. Apps allow us to monitor our exercise, view test results, chart our cognitive progress, and sign up for clinical trials, all by clicking on our smart phone.

In this edition of *The Transmitter*, we get a clear view of some of the exciting new developments in PD treatment, both in the hospital and right “at home” on our personal computers.
Telemedicine Update

Meredith Spindler, MD

Just as technology has led to globalization by connecting people at anytime, anywhere, technology can also help doctors deliver care to anyone, anywhere. Many people with PD do not have access to specialty care, either because of distance, inability to drive or transportation, or immobility.

In fact, it is estimated that approximately 40% of PD patients who are U.S. Medicare beneficiaries do not see a neurologist, let alone a movement disorders specialist. As a result, routine screening for falls, difficulty swallowing, and medication side effects may not be adequately monitored in these patients. People with PD who do not see a neurologist are more likely to require nursing home placement, and have a higher risk of hip fracture, hospitalization, traumatic injury, and urinary tract infections. Furthermore, complex treatments for Parkinson’s, such as deep brain stimulation therapy, carbidopa-levodopa enteral suspension, and clinical trials, may not be offered.

Telemedicine visits offer a creative way to provide more care, even when patients are not physically with their providers. Videoconferencing technology makes it possible to conduct a visit similar to your in-office visits with your doctor. Encrypted software has been developed to allow providers to do this without endangering patients’ confidentiality and privacy. Advances in technology have allowed providers and patients to have a visit with just two smart phones and an Internet connection, just like a Skype or FaceTime call.

What Happens in a Telemedicine Visit?

PD is uniquely suited for telemedicine visits, since the physical exam is mostly visual. Though at your routine visits your doctor may move your limbs around to assess your tone, and pull you backwards to test your balance, the majority of information necessary to make management decisions can be gleaned from listening to patients’ reports of symptoms and watching their movements. Studies of telemedicine visits have validated this “remote” neurologic exam for Parkinson’s patients, and have found that patient and provider satisfaction with telemedicine visits is on par with, if not greater than, in-office visits.

Telemedicine can be used to conduct routine follow-up visits every 4–6 months, initial consultations in the case of homebound cases, or even to alternate with in-office visits so that patients see their provider in person at least once a year but in the interim do not have to travel.

Am I Eligible for Telemedicine?

To be eligible, you will need a computer, laptop, tablet or even a smartphone (but the image will be very small), with a webcam (most laptops and tablets have webcams built in). You will also need a broadband internet connection, which can be cable or wireless. The device should have a relatively new operating system and internet browser. The software can be downloaded when you receive an email invitation to the visit.

How Much Does It Cost?

Currently, Medicare and most private insurers do not reimburse for telemedicine visits for Parkinson’s disease. Advocacy groups have been lobbying Congress for years to have Medicare reimburse telemedicine visits, and it is likely that this will happen in the near future, with private insurance companies following suit.

Until this occurs, the PD&MDC will continue to conduct telemedicine follow-up visits on a limited basis, free of charge, for homebound patients or those in remote areas. However, patients with commercial (non-government) insurance who reside in Delaware can be seen via telemedicine and pay their regular office visit copay. By the end of 2017 the PD&MDC will also likely be able to conduct telemedicine visits for a fee, via a self-pay mechanism that bypasses billing insurance.

For more information, please call Jennifer Negron at 215.829.6708.
There is a wealth of research and information praising the role of exercise in the daily lives of people with Parkinson’s. A lion’s share of the literature points to the combination of daily exercise and appropriate medication as the best way to not only manage both motor and non-motor symptoms, but to slow disease progression.

We all know we need to exercise, but changing lifestyles and behaviors is always a challenge. Thankfully, the tech industry has revolutionized the way people exercise. It seems as though there are apps for everything: track your exercise, track your symptoms, track your meds, and track your sleep. There are even apps to help you meditate and remind you to breathe!

With so many options, it’s hard to not get overwhelmed. Trackers, pedometers and apps can all be very useful tools to help you reach your fitness goals—if you use them wisely. Here are a few tips to keep your tracking on track:

1. **Start simple.** Many of the new fitness trackers and pedometers are so easy to use, you just put them on and start walking. If you’re not tech-savvy, have a friend help you download the accompanying app to your phone and get busy using it as you progress towards your goals!

2. **Find an app that tracks more than one thing.** Having an app to track your walking, one to track your cycling, and one to track your Zumba classes can be more time-consuming than actually exercising! Apps like Strava and Map My Fitness track multiple activities and give you daily reminders to keep moving.

3. **Engage in some friendly competition.** Research overwhelmingly says that if you exercise with a friend it keeps you accountable and helps you stick to a plan. Most trackers and apps have a social media component where you can share your activities as well as compete in challenges with your friends. Keep it fun and remember, you’re in this together!

If you’re still feeling overwhelmed or need an extra kick-start for your routine, contact your physician about getting a prescription for outpatient therapy services and make an appointment with the therapy team at Dan Aaron Parkinson Rehabilitation Center. We are more than happy to help you learn how to use these devices and help you take the first step toward a healthier and happier new you!

**AN APP TO CHANGE Behavior in PD Patients?**

Nabila Dahodwala, MD

Smart phones help us communicate with each other, and also offer new ways to navigate our daily lives. New developments in technology for disease management are particularly exciting, and there are currently over 165,000 healthcare apps available to consumers on Apple and Google platforms. Smartphone applications have great potential benefits for people with PD and their families to improve quality of life in a safe, inexpensive and efficient manner.

There are four major categories of healthcare apps:

- symptom assessment and monitoring (also known as wearable sensors)
- disease self-management (for example, medication reminder alerts)
- exercises/games (for example, dexterity exercises)
- education

Although healthcare apps help educate and keep patients on track, there has been little research into their effectiveness in changing how people with Parkinson’s or their family members feel. To that end, Dr. Dahodwala and colleagues at Penn Medicine are testing a new health app designed to improve goal-directed behavior and reduce signs of apathy or loss of motivation in PD. The goal of the app is to offer coaching, patient-provider communication and feedback, and built-in rewards with the end result being increased accountability for self-care. Currently, we are pilot-testing the app to determine its feasibility and usability. This project is funded by The Parkinson Council.

Please contact Chinwe (ChiChi) Nwadiogbu at 215.829.7733 for more information about this study.
The symptoms of Parkinson’s disease vary from person to person, and can change over the course of a day. As PD progresses, patients can develop motor fluctuations in which they alternate between periods of ON time, when Parkinson’s medications are improving symptoms of slowness, tremor and stiffness, and periods of OFF time, when the symptoms return. Dyskinesias, or excess movements, can also occur.

During clinic visits, we perform examinations that provide a snapshot of a patient’s symptoms, but clearly, there are hours of symptoms that must go unmonitored. Wearable devices and smart phone applications offer a new approach to tracking symptoms for better treatment management. We are developing ways to use wearable devices and smart phone applications to identify changes in a patient’s symptoms (ON, OFF or dyskinetic).

In our study, we will be using the XEED devices, which are small sensors, worn on the wrists and ankles, developed by an engineering team at Penn. These sensors continuously collect and record information about a person’s motor symptoms and movements. We will also be using the mPower application, which involves completing five tasks (memory, walking, tremor, tapping, and voice task) on a smart phone. For this study, participants will wear the XEED sensors and perform the mPower tasks in a monitored setting. Participants will also have the opportunity to wear the sensors at home for two weeks, and to continue their mPower tasks at home.
MARCHING TO THE BEAT of a Metronome in PD

Thomas Tropea, MD, and David Coughlin, MD

Many of us are familiar with those hours we spent at the piano as children, trying to get the rhythm of the music by listening to the relentless beat of a metronome. As it turns out, this device can be of use to people with parkinson’s (PWP) who experience freezing followed by “festination,” or little stutter steps.

Some PWP are well aware of these episodes, where their feet feel stuck or glued to the floor, and suddenly they burst into action with tiny quick steps. This is called “freezing of gait.” This problem occurs most often when getting up from a chair and starting to walk, when turning around, or when in tight or crowded spaces. Sometimes freezing of gait can improve with the medications we use to treat PD.

However, for others, freezing of gait does not completely go away. There have been a handful of studies looking at metronomes used to help people break the freeze. In our lab at the University of Pennsylvania, we are currently enrolling patients with PD who experience freezing of gait that does not improve completely with medication. We are interested in whether a vibrating metronome that buzzes at a given frequency can help these patients. Participants enrolled in this study come into the clinic for a one-time visit and answer some questions related to freezing of gait. Then they take a brief evaluation of their thinking and memory.

The next step is wearing a vibrating metronome and walking around a course that has triggers for freezing while we videotape the patient. The visit typically takes less than an hour to complete.

We are still looking for another 20 patients to enroll! Please contact Dr. Thomas F. Tropea or Dr. David Coughlin at 215.829.7273 if you are interested in learning more about this study.

The data collected from these devices will help us monitor symptoms over time and give us a better picture of how a person is doing from day to day—and can pinpoint when they are ON, OFF, or dyskinetic. This information can help clinicians track the effectiveness of medications and identify time periods of worsening symptoms where medication changes may be beneficial.

In addition, these devices can provide patients and care-partners with feedback and help improve their overall understanding of their disease. Projects like this may help us build a more personalized approach to treating each individual patient at our Penn Parkinson’s Disease clinics.

For more information or to sign up for the study, please contact Jacqui Rick at 215.829.7778.
Josue Etienne, RN, graduated from Penn State University with a bachelor of science in nursing (BSN) and has been practicing as an RN for almost 5 years. His background in nursing includes neurology, neurosurgery, trauma, and psychiatric medicine. He is ecstatic about becoming a member of the neurology team here at Penn Medicine where he will be working as the clinical nurse coordinator for the PD&MDC. Josue hopes to contribute to the success of the department and become a knowledgeable resource for all patients and their family members.

Katorah Williams, MS, joins the PD&MDC as a clinical research coordinator. She has a BS in neuroscience and psychology from Temple University and an MS in criminal justice from West Chester University. Currently, Ms. Williams is pursuing a doctorate in psychology at Immaculata University.

Mary Ann Thenganatt, MD, joins the neurology team at Penn Medicine Cherry Hill, and she will also see patients in our Pennsylvania Hospital location. Dr. Thenganatt received her medical degree from Boston University in Massachusetts. She completed her internship in internal medicine at the UCLA Medical Center in California followed by a residency and fellowship in neurology and movement disorders at Columbia University Medical Center in New York. Board-certified in neurology, Dr. Thenganatt specializes in the evaluation and management of movement disorders and is experienced in botulinum toxin and deep brain stimulation therapies.

David Coughlin, MD, is a movement disorders fellow at Pennsylvania Hospital’s Parkinson’s Disease and Movement Disorders Center (PD&MDC). He completed his neurology residency at the University of Pennsylvania and will be with the center until 2019. He treats Parkinson’s disease, parkinsonism, dystonia, ataxia, and other movement disorders. His research interests include early differentiation of Parkinsonian Syndromes and the contribution of Alzheimer’s pathology to PD and Lewy Body Dementia.

Derek Narendra, MD, PhD, is a movement disorders fellow at Pennsylvania Hospital and an assistant clinical investigator at the National Institutes of Health in Bethesda. He completed his neurological residency at Harvard. His research is focused on the genetic basis of early onset Parkinson’s disease.

WELCOME New Faculty and New Staff
**Accessible Program Workshops for People with Parkinson’s And their Care Partners**

**Philadelphia Museum of Art: A Show of Hands**

Participants will tour the museum galleries to learn about the rich symbolism of hands in art, including different styles and techniques artists used to render hands throughout various time periods and cultures.

This workshop will also engage in guided creative writing about the hands: what they do, what they have done, and what they will do. For more information on how to register, visit [http://theparkinsoncouncil.org/tpc-events/2017-04/](http://theparkinsoncouncil.org/tpc-events/2017-04/) or call 610.668.4292.

The Philadelphia Museum of Art Programs for individuals with PD are generously supported by The Parkinson Council and the Susan O. Jaffe Quality of Life Initiative.

**SAVE THESE DATES!**

**Parkinson’s Night at the Ballpark**

*Tuesday, May 9, 2017, 7:05 pm*

*Citizen’s Bank Park*

**Phillies vs. Seattle Mariners**

For information and tickets, email info@theparkinsoncouncil.org.

**The Parkinson Golf Classic**

*Monday, June 26, 2017*

*Huntingdon Valley Country Club*

Funds raised at this annual event support quality of life programs, research and comprehensive care. Call The Parkinson Council at 610.668.4292 for more information.

**10th Annual Flip Flop Walk**

*Saturday, July 15, 2017*

*Avalon Community Hall*

The Parkinson Council, in partnership with the Storbeck Family, is proud to celebrate the Flip Flop Walk in Avalon for the 10th year! For information, email info@theparkinsoncouncil.org.

**A Walk to Stamp Out Parkinson’s**

*Saturday, October 14, 2017*

*Philadelphia Zoo – New Venue!*

Join the largest community gathering devoted to raising funds in support of local people with Parkinson’s and their families. The dollars raised through this annual walk stay local to support comprehensive care at the PD&MDC at Penn.
The Transmitter is published biannually to inform the public about Parkinson’s disease and other movement disorders. The information contained herein is solely to raise awareness of developments in the field of movement disorders. Nothing written in this newsletter should be used as a guideline for treatment.

800.789.PENN
PennMedicine.org

UPCOMING EVENT

Jane Wright Patient and Caregiver Symposium
Thursday, June 15th, 2017
“Hot Topics in Parkinson’s Disease”
Hilton at City Line Avenue. Cost is $25.00 per person.
Please call 215.829.7273 to reserve a spot.

In April CELEBRATE Parkinson’s Awareness Month

Parkinson’s Awareness Month is for everyone you know…of course the idea is to build advocacy and also to keep fighting for a cure.

The Parkinson’s Disease and Movement Disorders Center is a National Parkinson Foundation (NPF) Center of Excellence.