Parkinson’s in a COVID-19 World

The introduction of the coronavirus into the US has changed our lives in extraordinary ways. And even though we’ve ALL had to change the way we work, socialize, and connect, people with Parkinson’s have felt the effects of this virus in more ways than most. That’s because when two of the activities we use to live well with Parkinson’s—connecting with others face-to-face and attending daily group exercise classes—are no longer an option, we lose critical wellness lifelines.

Therefore, over the past several months, we’ve done everything we can to make sure that people still have access to the activities that bring the most joy and health.

We moved our in-person events online and provided virtual ways for our community to interact. We’ve shared ideas on how to start and run support groups from a distance. We’ve offered examples of daily practices designed to keep people socially connected.

And we launched the virtual Every Victory Counts Challenge as a way to keep all of us focused on exercise, movement, and having fun. We know everyone is ready to get back to their pre-pandemic life, but until then, we’ll continue to adapt to the current crisis and do everything we can to keep our community connected and in action.

Ambassadors Connecting Digitally

When the pandemic hit and communities shut down, Ambassadors had to make significant adjustments from their in-person interactions, exercise classes, and support group meetings. Through these pivots, they have been able to help their communities in ways we have never seen before.

Stacey Macaluso in New Jersey moved her exercise classes online. Each week, Stacey sends out an invitation to members of her community for Davis Phinney Foundation events, webinars, and classes. She chooses something that is meaningful to the group and then sends resources the Foundation has on those topics. Additionally, Stacey planned for and executed the “Sidekicks Anytime” program virtually in May with help from their local youth academy, Kellman Brown Academy. Twenty-six students and nineteen people with Parkinson’s participated in the virtual program, and they hope to do more in the future. Stacey is just one great example of the work our Ambassadors are doing.

Stacey Macaluso in New Jersey moved her exercise classes online. Each week, Stacey sends out an invitation to members of her community for Davis Phinney Foundation events, webinars, and classes. She chooses something that is meaningful to the group and then sends resources the Foundation has on those topics. Additionally, Stacey planned for and executed the “Sidekicks Anytime” program virtually in May with help from their local youth academy, Kellman Brown Academy. Twenty-six students and nineteen people with Parkinson’s participated in the virtual program, and they hope to do more in the future. Stacey is just one great example of the work our Ambassadors are doing.

To learn more about our Ambassadors’ stories please email Sara Linn at slinn@dpf.org.
This year, going virtual hasn’t been the only change to how we have approached creating The Victory Summit event. With a focus on leaving a lasting impact on the communities we are connecting with, we have assisted in creating Community Action Committees (CAC) in several cities, including Baton Rouge, Louisiana, Omaha, Nebraska, and Albany, New York. The groups bring together local leaders from within the Parkinson’s community, including people living with Parkinson’s and care partners, to work together to address unique needs within their community.

People living with Parkinson’s are central to the success of these grassroots committees and have also been the highlight of each online event we have hosted. Peer speakers have delivered inspiring messages of hope and grounding at each event, and we’ve received countless comments from participants about how meaningful that has been. In addition to The Victory Summit event, Ambassadors and other local Parkinson’s leaders have hosted community workshops online to help people create living well plans and offer much needed support to care partners.

The need for social distancing has taken many of our activities and connections online and, while we absolutely miss connecting in person, one benefit of this shift has been that our national – and even global – Parkinson’s communities have seized this opportunity to become close collaborators and partners.

Since March, our Ambassador Program Manager, Sara Linn, and our Community Engagement Manager, Gabby Dimotsantos, have been leading a virtual connection forum for Ambassadors and CAC members. Through these meetings, community leaders that we work closely with have been able to connect with each other from across North America.

They share experiences, develop inside jokes, and learn new ways to serve the community by learning from each other.

In one of their first meetings, group members discussed how to support the community using digital platforms. After discovering that many members of the group did not know how to get started setting up virtual support groups, one CAC member stepped up to teach the others how it could be done. Within two weeks, everyone who attended the meeting was involved in virtual support groups with their community.

**2020 IMPACT**

With your support, so far this year we’ve reached nearly 477,000 individuals. From Team DPF events to Ambassadors and digital content, we’re spreading the message to more people than ever that you can live well with Parkinson’s.

**2020 HIGHLIGHTS**

- 17,224 participants registered for our Live Well Today Webinar Series. Topics we’ve covered so far this year include cognition and mood, pain, social connection, and more.
- 310,189 views on our YouTube channel and downloads of our podcast.
- 1,500 attendees for The Victory Summit events online for the Baton Rouge, Troy, and Omaha communities.
- 350 participants in the first-ever Every Victory Counts Challenge®.
- 29,804 worksheets downloaded from dpf.org.

**Creating Connections**

The need for social distancing has taken many of our activities and connections online and, while we absolutely miss connecting in person, one benefit of this shift has been that our national – and even global – Parkinson’s communities have seized this opportunity to become close collaborators and partners.

Get Involved! Contact Claire Herritz at cherritz@dpf.org or by phone at 303-953-4978 to learn more about upcoming events and opportunities.