

A Brief History: Mind and Motion for Parkinson's

Written by Rod Broker, Revised April 2019

Mind and Motion for Parkinson's is an education and support network for People with Parkinson's and their Care Partners in and around Marion County Florida. Most of the time we refer to our network as simply "M&M."

We who participate in the M&M network are, of course, not the first people in and around Marion County to experience Parkinson's Disease. Nor are we the first people in Marion County who have banded together to share resources and wisdom for managing this disease. But as important and as helpful as those past efforts were, key local leaders eventually moved on, and every one of those all-volunteer support networks in Marion County eventually collapsed.

In 2016-2017, several People with Parkinson's (PWPs) and their Care Partners met and talked, and became determined to fill the latest void for mutual PD education and support.

A steering team was formed in 2017, and Mind and Motion for Parkinson's came into being. Master the Possibilities (MTP), a lifelong learning center, was – and continues to be – gracious in offering meeting space for M&M gatherings. At the beginning, M&M had no income and, fortunately – as an all-volunteer organization -- no expenses! MTP even reached out to inform and encourage its many hundreds of registered students to participate in what M&M could offer.

At the beginning, the steering team determined that two-hour M&M gatherings would be held at MTP on the Last Friday of each month (except in December). These gatherings were first held in June 2017 and continue to the present.

In the first hour of our Last Friday events, guest presenters provide participants with information about the disease and resources for living with it. Medical doctors, researchers, therapists, clinicians, and social workers among others have shared their insights and knowledge and been there to answer questions.

In the second hour, participants form separate support groups (one for PWP's and one for Care Partners) to share their personal experiences, tips, successes and struggles. Almost immediately, 25 or so participants came together at these last Friday gatherings on a regular basis to form the M&M network.

M&M soon added a website (MindAndMotion.org) and flyers to our promotional and outreach efforts. But the most significant development was the On Top of the World recreation staff coming onboard to add "Move to Improve" - a strong Parkinson's-appropriate exercise component -- to our monthly gatherings.

By the beginning of 2018, the M&M steering team had been at work for more than a year, and more than 50 people were participating in the M&M network on a regular basis. A good thing was happening, and we were all benefiting from the "umpteenth" revival of a support and education network in Marion County.

To further raise awareness about M&M and Parkinson's Disease in our area, the steering team organized an April 2018 Walk for Parkinson's. More than 150 people came out to walk and to cheer for participants in their fight against PD. Furthermore, without any corporate sponsorship, over \$5000 was raised to support the education and research efforts of other existing Parkinson's organizations. After expenses, M&M kept nothing back to sustain its own efforts. What were we thinking? Or not thinking?

Shortly after Walk 2018, the steering team began to realize and articulate how fragile our own organization and structure was. The Walk had taken a lot of time and effort; worthwhile, yes, but almost exhausting. The M&M leadership team was predominately composed of PWP's and Care Partners. And anybody who knows anything about Parkinson's Disease knows how capabilities, time, energy and focus can change and diminish at any given moment.

We realized that if one or more existing key leaders needed to step away from the steering team because of a change in circumstances, the whole network might collapse, just as we had seen it happen before in Marion County. Appeals to the larger group of M&M participants, to step into leadership roles, bore little fruit because so many of their needs were already greater than their resources

By the Summer of 2018, the M&M steering team determined that we would need to find a path to sustainability. Too much good had been accomplished, too many people were benefiting from the M&M network, and too much work still needed to be done. We knew that we were seeing just the tip of the iceberg in terms of people in Marion County who need to know that they are not alone in the fight against Parkinson's Disease.

The loosely defined hope of the M&M steering team was that, in the future, we might somehow be able to engage a part-time executive who would spearhead our efforts and take some of the load off our volunteer shoulders. To accomplish this, we thought that Mind and Motion needed to become a non-profit entity and begin to receive tax-exempt donations that would undergird and extend the reach of our organization.

That governmental non-profit paperwork took all Summer to complete but, by Fall 2018, Mind and Motion for Parkinson's had developed bylaws, become a registered non-profit corporation in the State of Florida, and attained 501(c)(3) tax-exempt status from the IRS. Whew! We were on our way toward a greater chance of sustainability.

That same Summer of 2018, we began to interview several regional and national Parkinson's-related organizations to determine which one would receive the proceeds from our Walk 2019. That's how we discovered the Neuro Challenge Foundation (NCF). And very soon, we began to realize that an M&M/NCF partnership might be the solution to our need for sustainability and development. By Fall 2018, the M&M steering team and the NCF staff and board were well into negotiations to forge a partnership between us.

Here's what we of Mind and Motion saw in developing a partnership with Neuro Challenge Foundation: (1) NCF is a regional organization focused on serving the residents of Florida with its many and fast-growing number who are experiencing PD. (2) NCF knows its mission. So while other PD organizations work to support important research toward a future cure, NCF is committed to providing education and support for those living now with PD. (3) NCF knows what it is doing. NCF has active and committed board of directors as well as a compassionate, dedicated, and professional staff. (4) NCF is experienced. NCF has a long history of providing valuable service and resources to communities and

counties exactly like ours. (5) NCF doesn't rest on its well-deserved laurels, but wants to extend its mission and outreach into communities and counties like ours.

All that is good for us to know about Neuro Challenge Foundation and what they bring to the partnership. But a key feature of NCF's successful model and its significance for us will be the placement of what is called a "Care Advisor" in our community. In fact, Care Advisors are the key to NCF's effectiveness in every community and county that they serve within Florida.

We want to have an NCF Care Advisor in Marion County. The Marion County Care Advisor would be a paid person, employed by NCF to help M&M sustain and develop all the things important to us.

Our own Marion County Care Advisor will (1) help organize and facilitate our education and support gatherings; (2) provide objective and independent advice to individuals with PD and especially to those newly diagnosed or whose symptoms are progressing; (3) build relationships with other community health partners; (4) help to expand PD-related therapies and treatments; (5) generate financial support for M&M/NCF within Marion County.

The M&M Board of Directors has determined that Neuro Challenge Foundation is to be the recipient of proceeds after expenses from our April 6 Walk 2019. With the help of generous corporate sponsors and individual donors, we hope to raise \$10K-plus.

When these proceeds are forwarded to NCF, they will be deposited into an account designated to place, at least, a part-time Care Advisor on the ground in Marion County as early as May 2019. Everything depends on how much financial support can be raised and how much time they will be able to dedicate to our M&M network. Anything at all will be a start to M&M's goal of greater outreach and long-term sustainability.

Perhaps other communities or areas within Marion County will also want to get involved in partnering with Neuro Challenge Foundation. The need is so great all over Marion County. Maybe other PWP's and Care Partners in other parts of Marion County and beyond also need a path to a more enduring, more sustainable, more effective approach to helping those who are fighting the effects

of Parkinson's Disease. Maybe we could work together with NCF and reach every PD household in every corner of Marion County and beyond.

As of May 2019, there are over a hundred-plus participants on a fairly regular basis connecting to our M&M network. We have now a Board of Directors, not merely a steering team. We know what we want to do, and we know what we want to become. Despite shaking and bending and often stalling in our footsteps, we want to grow stronger and smarter and more effective. But we also know how easily and quickly all our efforts could grind to a halt. Time is of the essence.

By partnering Mind and Motion for Parkinson's with Neuro Challenge Foundation, we hope to sustain and expand our efforts in and around Marion County until that hoped-for day in the future when there is once and for all a cure for Parkinson's Disease. Until that day, M&M and NCF, we have our work to do -- together.