

Establishment of InMotion, an independent, fee-free community center for persons with movement disorders



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BACKGROUND

1. The need for lay information about movement disorders guided by knowledgeable parties grows. For example, the definition of Parkinson's disease has undergone significant revision in recent years, in large part driven by expansion of knowledge about motor and non-motor manifestations, and their treatment.
2. Extensive research has shown the value of physical activity for PD, but patients have difficulty finding places where they can comfortably carry out recommendations of medical personnel.
3. Many major communities have wellness centers devoted to patients and families afflicted with cancer. These centers provide considerable information and support services at no cost to the recipients. These centers are financed by philanthropy.

THE PLAN

Our concept was to develop a community center for persons with movement disorders in the greater Cleveland area. There were to be 3 main components: a varied physical activity program, a medical education and advisory presence, and a community wellness center. The center was to be independent of any specific healthcare system, in order to welcome people regardless of their doctors' location. All services were to be provided to the public at no charge. Facility operations, administrative salaries, instructor fees and other expenses were to be fully supported by philanthropy.

KEY DESIGN FEATURES

- We believed the following policies and strategies would be critical to our success:
1. Fee-free access to all programs and services
 - Our goal was to remove as many barriers to participation as possible
 - All offerings are provided to the community free of charge
 2. Nonprofit status
 - We received federal government recognition as a nonprofit institution, providing early legitimacy to our efforts and tax benefits to our donors
 3. Location
 - Our center is immediately adjacent to an existing physical fitness facility that had previously worked with people with Parkinson's disease
 - The experienced training personnel of this adjacent facility conduct InMotion's exercise classes without travel constraints
 - An added bonus of this location is its proximity to both north-south and east-west major highways, enhancing access from regions near Cleveland
 4. The physical activity program
 - A major emphasis was to provide a program consistent with research documenting the value of physical activity in Parkinson's disease
 - The program was to offer as varied a selection of physical activities as possible, guided by research demonstrating their specific value
 - Instructors were to be certified in their respective disciplines and paid on an hourly basis
 5. The Board of Directors
 - The Board was to be composed entirely of volunteer members of the community at large with diverse areas of experience and expertise critical to the establishment and ongoing operation of a new nonprofit venture
 6. Construction design
 - Great care was taken to design a facility that would welcome people of varying levels of mobility, and provide accommodations for all services
 - We have a large multi-purpose room for classes and presentations, an educational resource room, a living-room-style lobby, two smaller meeting rooms, the medical director's practice office, two private massage rooms, administrative offices, a kitchenette and wheelchair-accessible restrooms
 7. The educational program
 - A regular series of presentations regarding disease-related and other topics of interest to persons with movement disorders
 8. Financial development
 - A critical aspect of our fee-free model requiring ongoing, broad-based requests to philanthropic funds and private individuals for support

RESULTS

1. Important milestones
 - April 22, 2013: First meeting of founders
 - Late 2013: Invitations to prospective members to join Board of Directors
 - January 6, 2014: Initial meeting of the Board of Directors
 - Spring 2014: A large donation from the Allan Goldberg family permitted hiring an architectural firm and construction of the center
 - March 11, 2015: First exercise class held at InMotion
 - April 23, 2015: Grand Opening of InMotion center facility, 2 years after initial discussions and less than 16 months after initial Board of Directors meeting
 - October 2015: Expansion of program offerings from 3 to 5 days per week (permitted by a large grant from the Cleveland Foundation)
2. Philanthropic support
 - One year after opening, InMotion has been pledged a total of US\$1.5 million, of which US\$1.2 million has been collected
3. Program offerings
 - Daily: exercise ("Better Every Day") stratified into 3 intensity levels, cycling
 - Weekly: boxing (3 X), modern dance (2 X), ballroom dance, yoga, tai chi, meditation, singing, Lee Silverman Voice Therapy maintenance, meditation, art workshop, separate support groups for patients and care partners
 - Monthly: medical and non-medical presentations
 - Special events
 - Other resources and services: mentorship program for newly diagnosed patients, educational facility with desktop internet access, massage
4. Attendance
 - In the first 15 months, over 600 "clients" were listed in our database
 - Over 12,000 visits to all program offerings were registered, with a current rate of around 1,000 visits per month
5. Contributions of members of the Board of Directors
 - A real estate attorney negotiated our lease and drew up articles of incorporation
 - A chartered accountant serves as treasurer, producing financial reports and organizing audits to maintain our nonprofit financial compliance
 - A nonprofit executive obtained access to local philanthropic funds and wrote our early successful grant applications
 - The medical director provides a monthly series of lectures on movement disorders for lay persons, plus advice on medically related affairs that arise in general media or local enterprises
 - Other Board members provide many vital services including administration, fundraising, developing an online presence, organizing special events, and establishing liaison with other institutions nationally and internationally, all on a volunteer basis
6. Additional observations
 - Surveys of participants at InMotion indicate that one of the primary benefits they experience at our center is a sense of welcoming and camaraderie with others
 - It is our impression that we have created a new community for persons with movement disorders in our area
7. The future
 - Our program will continue to evolve to meet the needs of our community
 - Outcomes research is underway
 - We have hired a Chief Advancement Officer to spearhead a sustainable development program and coordinate publicity and marketing
 - We feel many metropolitan areas could support similar facilities, and hope to serve as a model for others wishing to establish such a center elsewhere

CONCLUSION

It is feasible to open and operate a comprehensive community center for persons with movement disorders, independent of existing institutions with other missions and agendas. This model depends on the dedication of many individuals with varying backgrounds to raise funds, set and execute programs, and operate the facility. Nevertheless, our experience with the enthusiasm and support of our clients and the general community convince us that the effort has been highly worthwhile.

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