



**Allied
Team
Training
For Parkinson**

A program of the National Parkinson Foundation

Needs Assessment Statement

The National Parkinson Foundation (NPF) developed its signature national training program, *Allied Team Training for Parkinson (ATTP)* in response to documented needs. Not only did its network of 64 Centers and grassroots chapters informally report that medical, nursing and allied health professionals in their regions of the U.S. were uninformed about the signs and symptoms of Parkinson's disease and the latest assessment and treatment approaches, but raised concerns as well that there were people in diverse and rural communities who were not receiving informed Parkinson's care. Since then, ***there is a growing body of evidence to suggest that continuous learning opportunities are needed to help clinicians provide high quality and informed care, particularly in a complex chronic illness such as Parkinson's disease.***

The following briefly reviews literature on evidence of need in a host of areas, include (a) the status of the broader healthcare system, (b) need for knowledge about evidence-based practices, (c) need for improved understanding of the complexities of Parkinson's disease, its management, and its impact on quality of life, (d) need for team-based approaches in Parkinson's care, (e) evidence of health disparities in healthcare services, and (f) documented essential principles of adult learning in developing continuing education opportunities.

The Broad Picture of Healthcare System Needs

» *The workforce is unprepared to meet current and future healthcare needs of a changing and aging U.S. population.*

The Institute of Medicine (IOM) is a leader in systematic studies of need in the healthcare system. In *Crossing the Quality Chasm* (2001), the IOM notes that "millions of Americans fail to receive effective care" (2001, p.3) and points to a need for fundamental change in the way healthcare is delivered. Care that is evidence-based and patient-centered, timely, efficient and equitable, currently inconsistently provided across today's healthcare system, is the goal of a high quality healthcare system. Among some of their recommendations are to:

- » redesign healthcare processes to better serve the needs of the chronically ill for coordinated, seamless care across settings and clinicians over time,
- » ensure that the healthcare workforce has the needed skills and knowledge, and
- » advance the effectiveness of teams

The number of older adults in the U.S. will almost double between 2005 and 2030 (IOM Brief Report, April 2008). In 2007, IOM charged an Ad Hoc Committee on the Future Health Care Workforce for Older Americans with determining, in view of an aging population, the healthcare needs of Americans over age 65. The report concludes that the current healthcare workforce has received little training in geriatrics and is essentially unprepared to meet the healthcare needs of the older adult population, and most especially of those with complex and chronic health issues. The report recommends enhancing the geriatric competence of the entire

workforce. Other recommended responses to need were significant “enhancements” to educational curricula and training programs, comprehensive programs to meet the healthcare needs of older adults and healthcare teams which include patients and informal caregivers as “players” on the healthcare team.

The Move Toward Evidence-Based Medicine and Core Competencies

In the Learning Healthcare System (2006), an IOM Committee notes that more information is needed to guide clinical decision-making, as patients are more heterogeneous and disease management is increasingly complex. Evidence-based medicine, integrating clinical expertise with the best available external evidence, emerged in the 20th century as a methodology for improving care. Yet, IOM notes that many clinicians are unaware of evidence-based best practices and thus, unable to adopt them into practice. They recommend helping clinicians bridge the knowledge gap through continuous learning and more rapid dissemination and diffusion of innovation into everyday practice. An interesting study of occupational therapists (OT) in Australia (McClusky and Cusick, 2002) found that OT clinicians in their sample did not know what evidence-based practice meant and lacked the skills, time and access to databases to search out and adopt best practices. The author further noted that “there is nothing to suggest that occupational therapists behave any differently to other health professionals, for example physiotherapists or general practitioners” (2002, p.64), concluding that attending continuing professional development courses is one important way to bridge the research-practice gap.

Yet another IOM publication, Health Professions Education: A Bridge to Quality (2003) outlines a core set of competencies and knowledge to be integrated into health professions education, including:

- » Patient-centered care
- » Interdisciplinary teams
- » Evidence-based practice
- » Quality improvement, and
- » Informatics

They note several challenges faced by today's clinician, including:

- » the need to be more skilled in responding to varying patient expectations and values,
- » readiness to meet a more diverse, aging and chronically ill patient, and
- » an expectation to work in teams despite not being trained in team-based skills.

In all, then, the literature clearly points to the need for high quality continuing education opportunities to address gaps in the preparedness of health professionals.

The Complexity of Parkinson's Disease and Need for Continuing Medical Education

Health care professionals lack understanding of the symptoms of Parkinson's disease, its complexity and current treatment and management approaches over time.

By now, there is considerable literature outlining the complex, varied and debilitating course of Parkinson's disease (PD), impacting both those diagnosed and their caregivers and families. At the earliest stages, understanding the impact of the diagnosis, effective explanation of the condition and the need for early referral to Parkinson's-trained specialists has been highlighted (Playfer, 2000; Stewart, 2007). Understanding and managing complex motor symptoms such as

rigidity, postural instability, freezing and on-off cycles require specialized knowledge of complex medication management strategies and other treatment approaches. There is increasing recognition too of the significant impact of non-motor symptoms and the difficulty in managing symptoms such as depression, anxiety, apathy, cognitive changes and, at later stages, neuropsychiatric symptoms such as hallucinations, psychosis, dementia, and medication-induced impulse control disorders. And, there is a growing literature outlining significant caregiver strain, particularly with disease progression, and significant impact on quality of life, most especially contributed to by symptoms of depression and cognitive impairment (Rahman, et al, 2007). Cheng, et al (2007) reviewed the medical records of 401 Los Angeles veterans with Parkinson's disease to see if care met key indicators of Parkinson's care quality. Differences between movement disorders specialists and non-neurologists were especially large on four indicators: wearing off, assessment of falls, depression and hallucinations. The authors note that providers are unaware of treatment and thus, do not provide recommended care.

Despite this complex and varied picture, evidence indicates that, as access to specialty care declines, primary care physicians play an increasingly important role in Parkinson's care (Parkinson Society Canada, 2004), often with little or no training in PD. A Boston Life Sciences publication notes that approximately 140,000 individuals present to physicians with new and undiagnosed movement disorders such as Parkinson's disease and Essential Tremor. In a presentation to the Parkinson Action Network in Washington, D.C., Dr. Mark Hurtt, Chief Medical Officer of the Boston Life Sciences, noted that the error rate in diagnosis of Parkinson's disease among primary care physicians may go as high as 40-50%, and from 30-35% for general neurologists. A 2002 European Journal of Neurology article reported a 20-30% misdiagnosis rate in the early stages of PD, with others reporting even higher rates. Accurate early differential diagnosis has important clinical implications, including proper prescriptions for effective treatments and early referral for specialty care. Playfer (2000) notes that "misdiagnosis of Parkinson's disease causes stress for both patient and carer and can lead to unnecessary and potentially harmful drug therapy being instituted" (p.44). Decision Resources (2008) notes that a higher percentage of Parkinson's patients are left untreated in the care of primary care physicians compared with neurologists, noting that this may be a result of lower awareness among primary care physicians of the benefits of initiating dopamine agonists as a first-line drug, especially for younger patients in early stages of the disease.

A survey of 470 general practitioners, social workers and nurses in the United Kingdom assessed current levels of knowledge and future training needs (Parkinson Disease Society, August, 2008). The survey results showed a lack of knowledge of mental health issues associated with Parkinson's disease among health and social care professionals in England. One third were not confident in identifying mental health symptoms in Parkinson's disease, and more than half had no training in this area in the last two years, but wanted to learn more (87%). The Parkinson Disease Society in England has developed a Parkinson's disease continuing education program to bridge the knowledge gap among healthcare professionals working with persons with Parkinson's disease. The course includes assessment and diagnosis, management of the disease and understanding of psychosocial issues attendant on PD.

The most recently published and first nationwide Parkinson's Knowledge and Needs Exchange Survey of a representative U.S.-based national sample of neurologists (October, 2008) uncovered critical needs for education on key issues in Parkinson's disease management. Among the study findings were significant communication gaps between neurologists (criteria for their selection included seeing minimum of five Parkinson's patients monthly) and persons with Parkinson's, with both requesting better tools and resources for improved disease management. One third of neurologists in the sample (total N=301) felt they lacked sufficient

information to respond to certain questions and issues raised by Parkinson's patients. Nearly one in four did not discuss healthy lifestyle changes with the person with Parkinson's or their caregivers. Up to 77% noted that they do not recommend clinical trials because they lacked information or study opportunities, although the vast majority (89%) was open to learning about them.

Thus, primary care and other physicians, as well as allied health professionals are often uninformed about Parkinson's disease and need further education about its complex management over time.

The Need for Comprehensive Team-based Care and Interdisciplinary Competencies

Health professionals are not trained in team-based multidisciplinary or interdisciplinary approaches to care so essential to meeting the needs of those presenting with chronic illness.

There is increased evidence that complex chronic illnesses are best managed through comprehensive and team-based approaches. Guidelines developed by opinion leaders in neurology and geriatric medicine (1998) identified multidisciplinary working as a fundamental strategy in Parkinson's disease for the primary care team. This parallels similar guidelines for Parkinson disease, developed in June, 2006 in the United Kingdom by the National Institute of Clinical Excellence (NICE), emphasizing multidisciplinary care as an essential care strategy. Menken (2004) too recommends the need for multidisciplinary teams in Parkinson's care, noting that general practitioners are often uncomfortable dealing with Parkinson's disease ("neurophobia"). He recommends "regionalization of care" such that Parkinson's-trained healthcare professionals can treat persons with Parkinson's in their own communities. Various IOM publications (2001, 2003, 2006) have pointed to lack of coordinated care and recommendations for team-based care as important strategies for dealing with increased presentations of chronic illness in the U.S. population. IOM has noted that interdisciplinary care is a critical 21st century competency for health professions (2003).

Despite this, there is ample evidence that health professionals continue to lack knowledge and skills in interdisciplinary teamwork (Belar, 2004). Health professionals are often trained in silos within their own profession, and need to learn about the role and contributions of other professions (Fealy, 2005). Educational opportunities are needed which can help them understand team-based care and how to implement that at their worksite.

As a complex chronic illness, PD requires the skills of multiple professions. Affecting as it does virtually every aspect of a person's life, PD encompasses motor and nonmotor symptoms, including depression, anxiety, apathy, autonomic nervous system symptoms, including sleep problems, orthostatic hypotension, constipation, etc. Playfer (2000) notes that treatment of PD requires significant teamwork and good communication, particularly between primary care providers and PD-trained specialists. He further notes that the general practitioner is often key in accessing appropriate care. Playfer suggests establishing accurate diagnosis in collaboration with a specialist and using a shared-care approach by building strong collaborative networks early in the diagnosis with the continuous care team of professionals.

In a survey of agreement between primary care physicians, general neurologists and neurologists about whether and when to refer to a specialist, there was considerable disagreement, most especially in PD case scenarios (Swartztrauber, 2004). A number of primary care physicians preferred to remain the central coordinating/treating source for PD patients and families, rather than referring to a neurologist or movement disorders specialist.

In view of this, it is clear that primary care physicians would benefit from attending courses which help them to better understand PD staging, diagnosis and current treatment strategies.

Health disparities in Parkinson's Care: Reaching Diverse and Rural Communities

While studies of health disparities in Parkinson's care are limited, informal reports suggest that diverse and rural communities are not receiving informed Parkinson's care.

The IOM publication Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare (2003) essentially served as a call to action by highlighting evidence of health disparities in a wide variety of health conditions. While there is no formal study of health disparities in Parkinson's care to date, there are some (although limited) epidemiological studies in Parkinson's disease (Van Den Eeden, et al, 2003; Mayeux, et al, 1995) that estimate PD incidence rates. Van den Eeden has demonstrated that incidence rapidly increases with age, with the rate, in his Northern California sample, for men being 91% higher than for women. In their sample, Hispanics had the highest incidence rate of PD at 16.6 per 100,000, followed by non-Hispanic whites at 13.6, Asians at 11.3 and Blacks at 10.3 per 100,000 respectively. By contrast, Mayeux, et al (1995) reported a higher incidence of PD in black men compared to Whites or Hispanics. While these authors concluded that incidence varies by race and ethnicity, both studies demonstrate that PD does exist in different racial and ethnic groups.

NPF Centers and Chapters have informally reported their concern that they were not reaching diverse and/or rural communities with information and specialized care. In response, NPF launched its signature national outreach program, National Parkinson Care Network (NPCN) which has since reached tens of thousands of individuals in medically underserved communities with information about Parkinson's disease. ATTP too has trained providers working in diverse and rural communities, as IOM (2003) has suggested that residents of diverse and underserved communities often prefer to receive care in their local settings.

The publication Health Connect: A Practical Guide to Community Outreach (González-Ramos, et al, 2007) serves as a guide (and a free handout to trainees) to building culturally competent community connections for the Day 5 ATTP curriculum module on Building Community Connections. The intent is to help trainee-providers link with local communities and build regional networks of care in Parkinson's disease.

Essential Principles of Adult Learning

Continuing education needs to incorporate key principles of adult learning for effectiveness and address changing continuing medical education mandates for education designed to affect change in practice behaviors.

There is considerable literature outlining key principles of adult learning which correlate with effective training and continuing education programs. Kaufman (2007) neatly summarizes essential adult learning characteristics, based on educational theory, to guide effective teaching and learning opportunities in medicine, including the following:

- » *self-directed learning* which empowers participants and encourages them to accept responsibility for their own learning rather than allowing them to be passive recipients of knowledge

- » *self efficacy*, giving them basic knowledge and skills and utilizing modeling and demonstration as teaching tools
- » *reflective practice*, and particularly *reflection in action* (while the event is occurring) which helps participants develop “wisdom and artistry” in their practice.

The overarching theme is to involve learners in identifying their own resources and devising strategies that will be useful to them in achieving their own objectives. As a correlate to that, he encourages participants to evaluate their own learning as well. These principles go a long way toward addressing new CME mandates for *active* (rather than passive) learning opportunities which are likely to promote change in practice behaviors (Pelletier, 2006).

The Allied Team Training for Parkinson program was developed to address the above noted needs and incorporates many of the learning principles recommended as part of current adult learning theory. Not only is ATTP content-specific in Parkinson's disease, interdisciplinary teamwork and how to reach out and build networks of care in the community, but it utilizes a varied and highly interactive format to convey knowledge and skill development. The course includes case studies, video and live interaction with persons with Parkinson's and caregivers, care planning in practice teams, intact teams completing SWOT analyses of their own team strengths, weakness and plans of action, etc. Discussions about dealing with their own institutional challenges in implementing team-based approaches are part of the training as well.

References

Belar, Cynthia (2004). The future of education and training in academic health centers. *Journal of Clinical Psychology in Medical Settings*. 11, 77-82.

Boston Life Sciences (February 19, 2006). Misdiagnosing Parkinson's disease. Press release. February 2006. http://parkinsons.hopedigest.com/blogs/misdiagnosing_parkinson_s_disease

British Geriatric Society (2007). NICE guidelines for Parkinson's disease. *Age and Ageing*, 376, 240-242.

Cheng, Eric M., Swarztrauber, K, Siderowf, A, Eisa, M, Lee, M, Vassar, S, Jacob, E and Vickrey, B. (2007). Association of specialist involvement and quality of care for Parkinson's disease. *Movement Disorders*, 22, 515-522.

Cheng, Eric M., Siderowf, A., Swarztrauber, K., Eisa, M., Lee, M. and Vickrey, B. (2004). Development of quality of care indicators for Parkinson's disease. *Movement Disorders*, 19, 136-150.

Decision Resources (July 17, 2008). Only 44.4 percent of Parkinson's disease patients receive drug treatment within one year of being diagnosed. News Release. July 17, 2008. http://www.decisionresources.com/press_releases.htm.

Fealy, Gerard (2005). Sharing the experience: Interdisciplinary education and interprofessional learning. *Nurse Education in Practice*, 5, 317-319.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.

_____. (2002). Who will keep the public healthy? Educating public health professionals for the 21st century. National Academy of Sciences: Washington, D.C.

_____. (2003). *Health professions education: A bridge to quality*. Committee on the Health Professions Education Summit. Washington, D.C.: National Academy Press.

_____. (2003). *Unequal treatment: Confronting racial and ethnic disparities in healthcare*. Washington, D.C.: The National Academy Press.

_____. (2007). *The learning healthcare system. Workshop summary*. IOM Roundtable on evidence-based medicine. Washington, D.C.: The National Academy Press.

_____. (Brief Report, April 2008). Retooling for an aging America: Building the health care workforce. National Academy of Sciences: Washington, D.C.

Kale, R. and Menken, M. (2004). Who should look after people with Parkinson's disease: Multidisciplinary teams are needed to address the needs of patients. *British Medical Journal*, 328, 62-63.

Kaufman, David (October, 2003). The ABCs of learning and teaching in medicine: Applying educational theory in practice. *British Journal of Medicine*, 326, 213-216.

Mayeux, R., Denaro, J., Hemenegildo, N., Marder, K., Tang, M., Cote, L. and Stern, Y. (1995). The frequency of idiopathic Parkinson's Disease by age, ethnic group, and sex in Northern Manhattan, 1988–1993. *American Journal of Epidemiology*, 142, 820-827

McClusky, A. and Cusick, A. (200). Strategies for introducing evidence-based practice and changing clinician behaviour: A managers toolbox. *Australian Occupational Therapy Journal*, 49, 63-70.

Parkinson Disease Foundation (October 7, 2008). *New survey uncovers critical need for education on key issues in Parkinson's disease management*. News Release. October 7, 2008. New York, NY. http://www.pdnewsclipper.com/2008_october8.htm

Parkinson's Disease Society (August 14, 2008). Parkinson's Disease Society project reveals need for training on Parkinson's and associated mental health issues for health and social care profession. *Medical News Today*. <http://www.medicalnewstoday.com>.

Parkinson Society of Canada (April 12, 2004). Canadians with Parkinson's face health care crisis: Patient population to double while number of doctors to decline. News Release. April 12, 2004. Toronto, Ontario.

Pelletier, Sue (July 1, 2006). Think bold. *Medical Meetings*. July 2006.

Playfer, J. (2000). Targeting Parkinson's disease: The case for early referral. *Current Medical Research and Opinion*, 16, 43-45.

Rahman, S, Griffin, H, Quinn, N and Jahanshahi, M. (2007). Quality of life in Parkinson's disease: The relative importance of the symptoms. *Movement Disorders*, 23, 1428-1434.

Stewart, David (2007). NICE guidelines for Parkinson's disease. *Age and Ageing*, 36, 40-242.

Swarztrauber, K and Vickrey, B. (2004). Do neurologists and primary care physicians agree on the extent of specialty involvement of patients referred to neurologists? *Journal of General Internal Medicine*. 19, 654-661.

Van Den Eeden, Stephen K. 1; Tanner, Caroline M. 2; Bernstein, Allan L. 3; Fross, Robin D. 4; Leimpeter, Amethyst 1; Bloch, Daniel A. 5; Nelson, Lorene M. (2003). Incidence of Parkinson's Disease: Variation by Age, Gender, and Race/Ethnicity. *American Journal of Epidemiology*. 157, 5-1022.