

European Guideline for physiotherapy in Parkinson's disease

Newsletter 2, July 2011

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What has been done, March to July 2011

- The survey has been set out in 17 countries, in 10 languages
- Members for the Writing Group, the Reading Group and the Review Panel have been selected
- Two persons with Parkinson's disease to complete the Writing Group have been successfully searched for
- The Writing Group has met (20 June) and discussed how to improve the current guideline
- The Steering Group has met and gained consensus about the project's process and products

Upcoming dates of interest

August 2011	Online forms for web-based surveys closed
November 2011	Newsletter 3 (e.g. introduction Reading Group members)
January 2012	2 nd meeting Writing Group

European survey nearly finished

In February 2011, the first web-based survey started, in Ireland. The last survey will be completed in a few weeks time. Here, we would like to share the first results with you. The final results will be prepared for publication, in collaboration with the participating countries.

The survey has now been set out in 15 countries, in 10 different languages. In each country, 600 randomly selected members of the participating ER-WCPT member organisations were addressed (*random survey*). With on average 209 therapists per country filling in the survey, the total response was 35%. In addition, therapists that might be Parkinson experts were addressed in person or via special interest groups (*expert survey*).

Responses from the random sample showed that most of the therapists treating Parkinson patients see less than 5 patients a year (Fig. 1), providing them limited opportunity to increase and retain expertise. The majority of the patients treated are past Hoehn & Yahr stage 2 (Fig.2). This was conform general barriers for providing optimal care reported, which include limited Parkinson specific experience and referral of patients at too late a stage. Other often reported barriers include limited time session, limited availability of local exercise groups and limited opportunity to discuss with other health professionals.

Figure 1 – Current care: nr of PD patients treated by physiotherapists each year

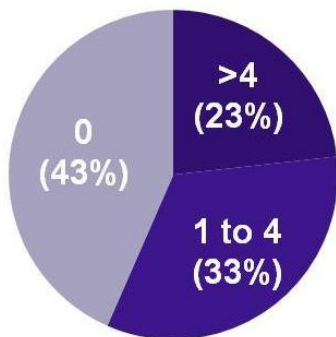


Figure 2 – Current care: Hoehn & Yahr stages of patients treated

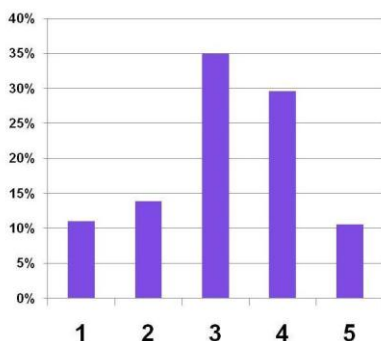
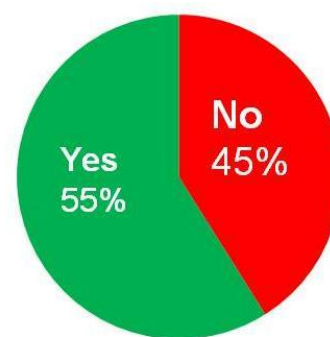


Figure 3 – Therapists treating >4 PD patients/yr: use of measurement tools



In total (*random survey plus expert survey*), we identified nearly 1.000 therapists treating at least 5 Parkinson patients each year. Only just over half of these therapists used measurement tools (Fig. 3). Not surprisingly, several barriers were reported in the use of these. In addition, these therapists shared a wide variety of other barriers in current care, which will be used to develop key questions for the new guideline.

Members Reading and Writing Groups selected

As described in the Project Plan (2010), all countries (ER-WCPT member organisations) participating expressed their preference for their representative to be in either the Writing Group (maximum 6 members in addition to the project leaders) or the Reading Group. Ten representatives preferred being part of the Writing Group. Given the quality and enthusiasm of all representatives, the selection was difficult. The basic selection criteria were: experience in treating PD; knowledge of epidemiology; capable of co-organizing the survey; and sufficient skills for speaking, reading and writing English. In addition, for a good geographic distribution, six regions were identified. All information provided by the representatives was used. In addition, Steering Group members were consulted. When based on this the selection could still not be done, the representatives were offered to contact each other for self-selection. The representatives finally selected for the Writing Group are presented in this Newsletter.

Patient participation in the guideline development

For nearly five years now, the Guidelines International Network (GIN) working Group GIN PUBLIC is collaborating with guideline developing societies, researchers and patients in order to develop recommendations for optimal patient participation in guideline development. Although a golden standard does not yet exist, a start has been made during the 2010 GIN congress, including:

- *Involve patients in all stadia of guideline development*
- *Have patients involved in a variety of roles, e.g. within a Steering Group, Writing Group and Feedback Group*
- *Let patient play a role equal to the other group members, therefore select patients who are equally equipped when it comes to e.g. communication skills and level of education*
- *Have at least two patients in each group, so they can be of support to one another*
- *Provide clear instruction to patients concerning the procedure, their options and responsibilities*

As Writing Group members need to be present at meetings in the Netherlands, Dutch patients have been searched for. We are delighted that two persons with excellent skills and expertise have agreed participate. In addition, patients will be involved through the Steering Group, the Reading Group and through open, web-based feedback requests.

Introduction Writing Group members

(in addition to Marten Munneke and Samyra Keus – see *Newsletter 1*)



Mariella Graziano, Representative of the Association Luxembourgeoise des Kinesitherapeutes (ALK)

After gaining her diploma in Physiotherapy in Argentina (1977) and the U.K. (1989), Mariella obtained her BSc (Hons) degree in the U.K. (1993). She is working with people with PD since 1977 and is running a neuro-physiotherapy practice from 1997 onwards. Over the past 10 years, she has organised and given workshops for people with PD, courses for physiotherapy in PD, and poster presentations at international physiotherapy, neurology and Parkinson's congresses. Since 2003 she is the president of the APPDE and board member of the EPDA. Also, since 2007, she is Vice-President of Parkinson Luxembourg (patient association) and, since 2009, member of Movement Disorder Society Health Professionals Working Group.



Jaana Paltamaa, Representative of the Finnish Association of Physiotherapists (FAP)

Jaana received her diploma in physiotherapy in 1984 and in specialized neurological physiotherapy in 1993. In 1994 she received her MSc degree in health sciences on a thesis on Parkinson's disease and finally her PhD degree on a thesis on Multiple Sclerosis in 2008. She has worked as a physiotherapist with neurological outpatients since 1989, seeing 150 to 200 Parkinson patients each year. Her focus was on the assessment of functioning, counseling and making rehabilitation plans. She has also worked as a research physiotherapist. In this, she has experience in the development of guideline aiming to enable client-centred, evidence-based therapy that is optimally timed and focused. Currently she is working in the JAMK University of Applied Sciences as planning specialist.



Bhanu Ramaswamy, Representative of the Chartered Society of Physiotherapy (CSP)

Bhanu received her diploma in physiotherapy in 1988. She continued to receive her PG Certificate in Neurological Physiotherapy (2005), a Practice Certificate in Non-medical Prescribing (2006) and finally her MSc in First Contact Care (2008). Currently she is an independent physiotherapy consultant and an honorary Visiting Fellow at Sheffield Hallam University. She has worked with Parkinson patients for the past 16 years and has carried out work for the Parkinson's UK. In 2009-2010 she led the adaption of the KNGF-Guideline Quick Reference Cards for the UK. Currently she carries out clinical physiotherapy (70%), academic tasks (20%) and research (10%). She is a member of AGILE (physiotherapists working with older people) and the Association of Chartered of Physiotherapists In Neurology (ACPIN).



Susanne Bruhlman, Representative of PhysioSwiss

After receiving certificates in General Education (1986), Business (1987) and massage and medical attendant (1990), she received her Physiotherapy diploma in 1993 (all in Germany). In addition, in 2010, she received her LSVT Big therapist diploma. Since her graduation, she has been working at one of the Swiss leading specialty hospitals for neurological rehabilitation, of which from 1999 onwards in the field of Parkinson's disease. She has organised several national courses and, in 2007, a congress based on the KNGF-Guidelines. She is member of the Swiss KNGF-Guideline Implementation Group and board member of the Swiss Parkinson Patient organisation. She developed the exercise DVD *Lets keep moving* for people with Parkinson's disease.



Elisa Pelosin, Representative of the Associazione Italiana Fisioterapisti (AIFI)

In 2001, Elisa received her Physical Therapy Academic degree on a thesis on Parkinson's disease, followed by a Physical Therapy Postgraduate degree (2004) and a Physical Therapy Master degree, again on Parkinson's disease. Since her graduation, she has worked as a physiotherapist in Neurology and Neurorehabilitation, and as a research physiotherapist (in both Italy and the U.S.A.). She has presented at many national and international congresses, been involved in physiotherapy training, and has published several papers. Currently she is working as a physiotherapy researcher and has started a PhD in Neuroscience. Also, she is a member of the Italian KNGF-Guideline implementation Group.



Josefa Domingos, Representative of the Associacao Portuguesa de Fisioterapeutas (APF)

Josefa received her degree in Physiotherapy in 2004, followed by a MSc degree in Neurorehabilitation in 2009. She is currently a PhD Student in Neuroscience (on Falls in Parkinson's disease) and is a researcher at the Movement Disorders Research Unit of the Hospital of Santa Maria. She has been exclusively working with Parkinson patients (10 to 12 patients a per day) for over 8 years and is running a Parkinson Disease NeuroPhysical Therapy Specialized Practice. She has been a speaker at different courses and national Parkinson congresses and was responsible for creating national physical therapy specialized services through the Portuguese Parkinson Disease Association. Also, she is a member of the Movement Disorder Society since 2009 and participated in several of its courses and congresses.



Chris Struikma, patient

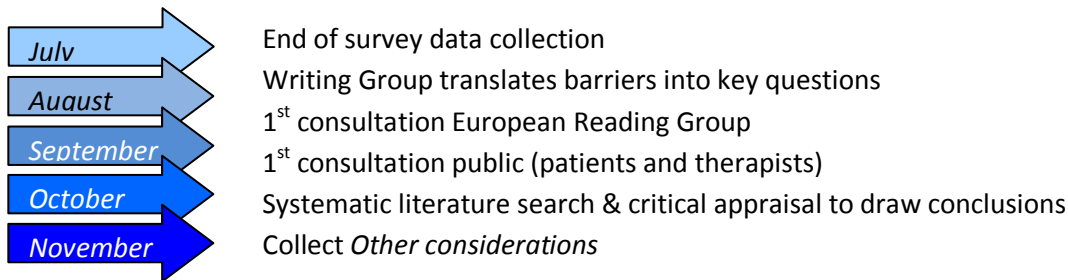
Chris Struikma is a psychologist (PhD), working as senior researcher. He is board member of the Parkinson Vereniging (Dutch Parkinson's Disease Society) and their taskforce Science and Ethics. He was a member of the Dutch Health Council working groups for dyslexia (1992-1995), ADHD (1999-2001) and autism spectrum impairments (2008-2009), as well as several steering committees for the Dutch College for Health Insurances (2002-2006). He is a member of the Feedback Group of the project Patient Participation in Scientific Research of the VU University Medical Centre (Amsterdam, NL). He participated in the World Parkinson Congress 2010 (Glasgow), and at the Year Symposium of the Parkinsonvereniging 2011 he presented *The patient's story*.



Jan Prins, patient

Jan Prins is a (sports)physiotherapist, manipulative therapist and health scientist (MSc). He is working as editorial member at Physios (post academic education) and is lecturer at the Leiden University for Applied Sciences. Until 2002 he worked as a physiotherapist in his own practice and as project employee Education at the Physiotherapy Science (MSc) of Utrecht University and University Medical Centre Utrecht. Presentations of interest: 'The patient within guidelines, Year Conference 2007 of the Dutch Society for Physiotherapy and Geriatrics (NVFG) and 'selfmanagement in chronically ill' at the Minisymposium Cluster Zorg hogeschool Leiden, 2011. Jan was diagnosed with Parkinson's disease in 2002. In April 2008 he received Deep Brain Stimulation(DBS).

Main activities until Nov 2011:



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