



WORLD PARKINSON CONGRESS

September 28 - October 1, 2010

SECC, Glasgow, Scotland

Bringing the Parkinson's Community Together

**Living with Parkinson's
Abstract Book**

This book is dedicated to **Divakar Deo** who passed away on June 6, 2010 while preparing his abstract for this book and his trip to the WPC 2010.

His inspiration to educate and empower his peers and community was outstanding as was his enthusiasm for helping people with Parkinson's in India. He showed an incredible spirit we hope will inspire others to continue to bring about change in their communities around the world.





Table of Contents

Welcome 4

Abstracts

Educational and Awareness Raising Programs (LWP1) 5

Government Advocacy / Campaigns / Public Policy (LWP2) 13

Living Healthier with PD (LWP3) 15

Influencing Research through Fundraising, Clinical Trials, Grassroots Campaigns (LWP4) 25

General Topics (LWP5) 26

Authors' Index 30



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Welcome

September 28, 2010

Dear friends,

It is with great pleasure that I introduce to you the first book produced by the World Parkinson Congress that includes abstracts about *Living with Parkinson's*. While the abstract section of scientific meetings typically focuses on the research side of Parkinson's disease (PD), we wanted to encourage learning from people living with Parkinson's and those who are living and working with people with Parkinson's as they are the experts on what it is like to live with PD day in and day out. Because of this we have two sections of abstracts this year: *Scientific* and *Living with Parkinson's*.

This book was only possible because of the outstanding efforts of so many people in the global Parkinson's community who are creating and running programs on a regional, national and even international level that help people with PD take charge of their disease. They do this through advocacy or campaign work, exercise and art programs, educational campaigns and other innovative collaborations. Not only are these people taking steps to bring about change in their communities, they have taken the extra step to share their work with you here, at the WPC 2010, through their abstracts. Our intent is to encourage dialogue between not just the scientists who are doing research, which is essential to finding the cause of and cure for PD, but also between all the people who are working to improve the quality of life of people living with the disease.

By sharing programs and campaigns with each other, we are able to learn from one another and understand how to start up, or expand, similar programs in our own communities. We can talk about what works, and what does not work, and how to go about making it all happen.

Be sure to visit this part of the exhibit hall to be inspired and to learn what people are doing around the world. We encourage collaborations and hope that if you do build a collaboration that starts here, you will share your work in the *Living with Parkinson's* poster section at the Third World Parkinson Congress in Montreal, Canada in 2013.

We would be thrilled to have you join us again.

Warm regards,

A handwritten signature in black ink that reads 'EAPollard'. The signature is stylized and cursive.

Elizabeth "Eli" Pollard
Congress Manager



Educational and Awareness Raising Programs

LWP1.01

Partnerships between Movement Disorders Clinics Nurses and Parkinson Societies across Canada: Positive Impact on Service Delivery

[Lachance, L](#)
Canada

Background: As we are all aware the gaps in services relate directly to the systemic barriers that exist for people living with Parkinson's disease and also with geographical context of this large country, we hope to address this issue with this proposal.

Objectives: This proposal of partnership between Movement Disorders Clinics across Canada and Regional Parkinson Societies Canada (PSC) is very much aligned to achieve the three specific goals of the PSC strategic plan. The specific goals are 1. Deliver and evaluate core services and education programs across all regional Societies based on the framework and standards that we already have. 2. Provide credible information and resources related to Parkinson's and care management that meet the needs of Canadians living with Parkinson's, in both official languages and 3. Increase the number of people served.

The purpose of the network is that the Movement Disorders Programs Nurses and Regional Parkinson Society Support staff will have an impact on the services throughout the country. Better dissemination of materials to allied health professionals and specialists in neurology or chronic disease, education and information sessions, referral process, better client education and information sessions, access to allied health professionals who are better informed in chronic disease (speech, occupational and physical therapy) and utilization of resources of community organizations.

Methods:

1. Creating a Referring Model: in order to address the issues a systemic process can be put into place to deliver a seamless model that allows clients/patients to manage their chronic condition with support and guidance. A team approach between partners must be developed so that clients have assistance in developing their health team, find valuable resources and use many professionals alleviating pressure and stress in the medical model.

2. Building a Network of nurses and mobilizing community partners: The idea of this network is to have access to a rich body of knowledge that we can all share information from one another to help patient and family, via webcast conferences, regular calls and emails and ideally one face to face meeting per year.

Discussion: From a quality of care perspective there is a necessity to work together and determined in consensus best practice guidelines and establishing a continuum of services model so people have support navigating through a complex health care system.

LWP1.02

Conductive Education and Parkinson's Disease

[Heine, M](#)

ITI UK, United Kingdom

Roots of Conductive Education

- Developed in the 1940s in Hungary by Professor Andras Peto.
- The Peto Institute was established to rehabilitate adults and children and to train Conductors.
- In the UK, a charity ITI UK was established in 1990 and Maria Heine was invited to England from the Peto Institute to establish Outreach classes for Parkinson patients. Wolverhampton University provide Conductive Education Conductors degree courses.
- Conductive Education classes are now held throughout UK.

What Is Conductive Education?

- A teaching methodology of learning and relearning motor skills.
- Conductive Education embraces learning and development of movement, speech, and mental ability simultaneously, not separately or consequently.
- It is educational. It teaches goals, values and motivation, plus skills. It is an all day, all life ongoing learning process.
- Conductive Education has five main elements to facilitate the process.
- It is conductive because the teacher, the conductor, leads the participants.

Why Choose Conductive Education?

- The system focuses on the effects of the condition for each individual person.
- Enables people to direct their own learning.
- Participants develop new and different ways of controlling the effects of the condition.
- Conductive Education helps individuals develop by giving them skills and motivation they need to overcome problems of movement in everyday life.

Elements of Conductive Education

- The Conductor. Follows an intensive 4 year university based 'hands on' performance training.
- The Programme. Aims to re-educate the personality as a whole by training the brain and body to work together. A day to day programme is planned of learning and practising.
- The Task Series. Tasks are taught, learnt, and practised. Guidance and user success lies with the individual.
- Intention and Rhythmical Intention. Language is used to plan, imagine, intend and implement movement. It controls speed and rhythm of movement.
- The Group. The basic unit in which the participants maybe matched for ability.



Educational and Awareness Raising Programs

LWP1.03

Communication, Cooperation, Community – The triple C rule to raise awareness on YOPD

Capitania, F

Unidos contra el Parkinson, Spain

Internet and the social networks can be turned into a powerful tool to:

- help organizations and institutions devoted to help Parkinson's patients and their families
- inform and educate people who use the Internet about the reality of Parkinson's (especially younger people)
- provide a communication platform between persons, associations, organizations, foundations that from a different angle are involved in the fight against Parkinson's disease
- mobilize energies and efforts to achieve goals that otherwise would fall outside the scope of traditional institutions, overcoming geographical, cultural and language barriers through the use of new technologies

The "Unidos Contra el Parkinson" project (Together against PD) started in January 2008 to achieve those targets following the "triple C" rule:

- Communication
- Cooperation
- Community

Working by projects, we defined one or more goals to achieve every year.

2008

Goal: Build a website to collect information about PD and build a PD social network.

Result: More than 700 registered users subscribe to our weekly bulletin and the website receives more than 6.500 visitors in the same period. (April 2010).

2009

Goal: Promote PD awareness through the 4th "Parkinson's Tour".

Result: 1200 Kms in 12 days biking for PD across Spain

Goal: Organize the Second UCP International Meeting in Spain

Result: 272 persons attended the opening ceremony of the event (October 2009), all the main events of the meeting have been broadcast live via the Internet for the benefit of those unable to personally attend, about 100 hours of therapeutic workshops in parallel sessions, a live radio program broadcasted, associations from 12 countries in the world have supported and informed about the meeting.

2010

Goal: Edit a comic to help families to explain the Parkinson "Through the eyes of a Child"

Result: March 2010, we edited and distributed 3000 units of the comic "Through the eyes of a Child".

Goal: Set up the largest educational event in Spain for PD community "Go ahead, It's your turn to Run for PD"

Result: April 25th more than 5,000 people in different cities running nearly 9,000 kilometers of solidarity.

Goal: Promote PD awareness through the 5th "Parkinson's Tour".

Result: 1000 Kms in 11 days biking for PD across Spain (July 2010)

LWP1.04

Addressing the Needs of Newly Diagnosed PD Patients:
Development of a Model Curriculum

Cook, DG; Vierck, E

¹Spark Foundation, United States; ²Information Associates, United States

Background: The Parkinson's Support Group for the Recently Diagnosed (PGRD) was launched on February 24, 2010 to an enthusiastic response. The group is sponsored by the Rocky Mountain Movement Disorders Center at the Swedish Medical Center's Colorado Neurological Institute in Denver, Colorado and the Parkinson Association of the Rockies.

PGRD meets once a month at the medical center. As an information gathering and sharing forum, the focus is upbeat and action-oriented.

Objectives: PGRD's project plan has three goals: 1. To provide opportunities for participants to ask questions and receive answers from physicians and other experts about issues and concerns unique to the recently diagnosed. 2. To provide a positive and supportive environment where members can share their personal stories and receive feedback and guidance from people in similar circumstances. 3. To develop a model curriculum for Parkinson's support groups for the recently diagnosed.

The third goal will be the subject of this poster, which will highlight three key components of a prototype curriculum: identification of topics, opportunities for building mutually supportive relationships, and medical advice designed specifically for the recently diagnosed.

Methods: Participants attending the opening PGRD meeting were asked to prioritize the issues that they wanted to discuss. The top five topics were: brain fitness, exercise, medications, apathy and fatigue, and adapting to PD. The list of topics will be refined throughout the project and will be the core of the curriculum.

PGRD's group meetings provide opportunities for members to foster supportive relationships with others in similar circumstances. And a panel of neurologists who regularly treat people with PD will be interviewed about their recommendations for what patients can do in the first few years after diagnosis to best manage their disease, slow down the progression of symptoms and foster neuroprotection.

Outcomes: Three major outcomes of the project are: 1. Informed PD patients making positive choices about the management of their disease and lifestyle and 2. Development of a model curriculum for support groups serving the recently diagnosed. 3. Wide implementation of the curriculum.

Conclusion: The burgeoning of support groups for the recently diagnosed will bring welcome attention to this group, whose unique needs are seldom noticed and often neglected.



Educational and Awareness Raising Programs

LWP1.05

Test your Parkinson's IQ: Parkinson Society Canada Awareness Campaign 2010

Snelgrove, B; Zacks, M

Parkinson Society Canada, Canada

Introduction: In 2010, Parkinson Society Canada celebrates 45 years of supporting Canadians living with Parkinson's. This poster presentation will showcase The Test Your Parkinson's IQ, developed for Parkinson Awareness Month. The goal of the campaign was to foster a greater understanding of Parkinson's disease and increase the number of people contacting the Society.

Method: Parkinson's is a complicated condition. We wanted to tell the public that Parkinson's is more than a movement disorder. We wanted to demystify the condition and talk about symptoms that are not usually associated with Parkinson's yet, for the person living with Parkinson's, can be more challenging: symptoms such as depression, changes in thinking ability, loss of sense of smell. The "test" included a simple checklist of 13 statements. The checklist was available on the national web site and also in print. People were also directed to an education piece that explained the symptoms in more detail. Since Canada is a bilingual country, all material was created in English and French.

Outcomes: The poster presentation will provide statistics on the success of the campaign. The presentation will show increased number of visits to the web site; links to educational resources; referrals to regional societies for further information and support. This innovative and creative "test", also received extensive media coverage expanding our reach and increasing awareness. Media also included interviews with movement disorder specialists talking about the importance of learning more about Parkinson's disease, especially the non-motor symptoms.

Authors: Barbara Snelgrove, Director, Education and Support Services and Marjie Zacks, National Director, Communications and Marketing

LWP1.06

The NeuroWriters' Guide to the Peripatetic Pursuit of Parkinson's Disease (PD): A Preview

Muralidhar, G; Wittekind, P; Kell, P; Huseman, K; Wheeler, J; Brooks, L; Herman, L; Citron, J; Willocks, P; Ashford, L; Cummings, R

¹Parkinson's Creative Collective, United States; ²Parkinson's Creative Collective, United Kingdom

Ten years ago, BrainTalk Communities, an online forum for Parkinson's disease (PD), offered an anonymous link to the world for newly diagnosed People with Parkinson's disease (PwP). For many with PD, the original BrainTalk Communities at Massachusetts General Hospital (hosted by John Lester) and the current NeuroTalk forums of Psych Central (hosted by John Grohol) provide a lifeline as well as much needed PD information for enhancing their quality of life. In tribute to these on-line forums and to share the wisdom and experience expressed in the archived BrainTalk and the current NeuroTalk PD threads, the NeuroWriters of Parkinson's Creative Collective (PCC) are collaborating on a book entitled, "The NeuroWriters' Guide to the Peripatetic Pursuit of Parkinson's Disease" (publication pending). PCC is a virtual organization (www.parkinsonscreativecollective.org) formed by eleven PwP volunteers, some of whom have never met face-to-face except virtually through NeuroTalk. They come from different walks of life - located in 10 U.S. states and the UK - with a common goal to provide information creatively and build global connections, hoping to change the current perceptions of living with PD.

"The NeuroWriters' Guide to the Peripatetic Pursuit of Parkinson's Disease" is uniquely designed with full graphics allowing each page to stand alone as both a story and a reference. It also gives readers a sample of the breadth and depth of the forum discussions, presenting the realities of PD directly from the PwP's perspective. The book challenges stereotypes, giving many examples of PwP who remain both mentally and physically active, educated about PD, and capable of thinking "outside the box". It illustrates how the members' collective intellect and quest to understand PD has resulted in novel ideas that are independently validated by the scientific community. The book also shows the emergence of the educated, engaged, and technologically savvy e-patient who wants to be a part of the research and development process. Finally, the book pays tribute to some of the PD organizations and individual pioneers in patient advocacy.



Educational and Awareness Raising Programs

LWP1.07

Blogging by People with Parkinson's Disease: An Assessment of Two Motivational Patient Blogs in Terms of Purpose, Positivity and Popularity

Kuhn, RG¹; Stamford, JA²

¹Canada; ²United Kingdom

Background: Analysis of patient blogs [1] discloses 3 main purposes. These are: (1) to share personal experience with PD (therapeutic/cathartic: 86%); (2) to advocate for awareness and/or funding in relation to PD (social/medical activism: 36%); and (3) to encourage, humour and challenge those dealing with PD (quality of life/motivational: 29%). We analyzed the similarities, differences and relative success of 2 intentionally motivational patient blogs.

Methods: Two patient blogs, Positively Parkinson's [2] (PP) and Slice of Life [3] (SoL) (Subject Blogs), self-characterized as motivational and similar in terms of authorship (age, family status, education and blogging history), general length and style, but dissimilar in country of origin, and blog hosting were compared for frequency of posting, positivity and popularity based on reported or accessed data from a three month period (Feb 3 – May 2, 2010).

Results: During the test period, differences in the number of postings (PP: 22/SoL: 13) produced general proportionality in total hits (PP: 3795/ SoL: 2519), daily hits (PP: 43.1/SoL: 28.6), while hits per posting were similar (PP: 172.5/SoL:193.8). The representative nationality of hits (PP: 24/SoL: 17 countries) was similar, with most (80+%) from predominately English-speaking nations, with majority being ethnic-similar visitors (=70%) and sharing similar visitor numbers from USA (=25%). Direct access (no referring site) accounted for 43.7% (PP) and 31.5% (SoL) of traffic. Google searches generated 19.9% (PP) and 0.7% (SoL) of traffic, while Facebook was responsible for 1.1% (PP) and 2.1% of hits (SoL). Referrals from wobblywilliams.com led to 6.4% (PP) and 61.0% (SoL) of hits. Subject Blogs reported receiving considerable response/comment affirming benefits to PD patients and others, but limited growth occurred month over month.

Conclusions: Intentionally motivational patient blogs are achieving their purpose, and trend to greater consistency of frequency, positivity and popularity than other patient blogs. However, expansion of readership and distribution of motivational/quality of life blog benefits requires increased promotion and awareness.

1 Heiferty CM. J Adv Nurs. 2009;65(7):1539-47.

2 www.positivelyparkinsons.ca

3 www.wobblywilliams.com/sol_blog.aspx

LWP1.08

Working and Crossing National and Cultural Boundaries to Spread Parkinson's Awareness

Capitaino, E¹; Burns, JE²; Martinez, C³

¹Spain; ²United States; ³Muhammad Ali Parkinson Center, United States

Background: Parkinson's disease (PD) has no boundaries. Fulvio Capitaino, PwP, of Spain developed the comic, "Through the Eyes of a Child" and it was printed and widely distributed in Spain.

Aim(s)/Objective(s): To work collaboratively using Social Media (email, Skype, Twitter, Facebook) to translate Through the Eyes of a Child and then present this work as a poster presentation at the WPC. Our ultimate goal is find funding and print and distribute this comic to the larger PD community worldwide.

Methods: Fulvio Capitaino, PwP, of Spain developed "Through the Eyes of a Child". Claudia Martinez, Hispanic Outreach Coordinator Muhammad Ali Parkinson Center, will provide the initial English translation of "Through the Eyes of a Child". Then Jean Burns, PwP, will work with Claudia to ensure the dialog is in idiomatic (American) English. Fulvio and Jean will collaborate using social media to create their poster and presentation for the WPC.

Results/Outcomes: Fulvio and Jean are using email, Skype, Twitter, and Facebook and other social networking tools as they work to coordinate this effort. Part of the poster presentation will be about what social media tools worked and what didn't work in their collaboration between Spain and the U.S.

Claudia will use the original version in Spanish for her support groups, and we hope to make the English version available to the English-speaking Parkinson's community around the world. Fulvio and Jean will present "Through the Eyes of a Child" by giving a synopsis of the story, and by role-playing.

Discussion: The comic "Through the Eyes of a Child" intends to offer a complementary tool for parents and grandparents to help them explain Parkinson's disease to their children or grandchildren.

When a family member changes behavior without offering an explanation, the balance of the entire group is compromised. What's happening at home? Which is the reason for all these mysteries? What can we do? Sometimes the answers will come in unexpected ways . . . through the eyes of a child.

Conclusion: Digital technology today would have been like magic 20 years ago. Having materials available to a worldwide Parkinson's community is important to both PwP and caregivers.



Educational and Awareness Raising Programs

LWP1.09

"POP-IN" A Rolling Educational Programme for Parkinson's Disease Patients and their Families

Thompson, C; Atkins, S; Utting, B; Amar, K
United Kingdom

Background and aims: Patient education and health promotion is regarded as important in complementing the medical management of patients with Parkinson's disease. Patients who are better informed are in a better position to make informed decisions regarding how they are managed and are able to cope better with the stresses of living with Parkinson's disease. The aim of this programme is to promote education and understanding of Parkinson's disease among patients and carers.

Methods: The PD team of Bournemouth and Christchurch in East Dorset (UK) introduced a rolling educational programme to help inform and educate patients and carers about PD. The programme consists of 13 sessions each lasting between 45 and 60 minutes covering the various aspects of PD. The sessions are multidisciplinary with input from specialist PD consultant, PD nurse specialists, a pharmacist, speech and language therapists, dietician, physiotherapist, occupational therapist, incontinence advisor and a social worker.

Results: The programme proved to be popular among PD patients and their carers, with an attendance of 40-50 subjects per session. Feedback from PD patients was very positive on the whole with a preference for more regular updates on new therapies and recent advances in the field of PD, such as stem cell research and surgery. This advice was later incorporated into regular "update" slots in the programme, which proved to be most popular among patients and carers.

Conclusions: A programme for education on the various aspects of PD is popular with patients and their families and is likely to result in a better overall management of these patients. There is a huge appetite among PD patients to learn more about recent advances and breakthroughs in the field.

LWP1.10

Music and Parkinson's Disease: "My Life"

Griffith, G
United States

Background: Grace Griffith has a singularly broad perspective from which to speak about Parkinson's disease. As a practicing physical therapist for 25 years, she had ample opportunity to observe effects of the disease in all its phases. When a brother was diagnosed with PD she began devoting focused study on the subject, and was surprised to discover a vast lack of knowledge and understanding about PD in the general public as well as among health care professionals.

Meanwhile Ms Griffith was cultivating a successful career as a singer, and signed a contract with Blix Street Records, the same company which brought Ireland's Mary Black and the late great Eva Cassidy to fame. (Cassidy was a fan of Griffith's, and it was Griffith who introduced Cassidy to Blix Street, resulting in her tremendous popularity in the UK and beyond.)

Then, in 1998 at the National Institutes of Health (NIH), Griffith was diagnosed with young onset Parkinson's disease at age 42.

Aims/Objectives: Griffith recognized early on that she was in a unique position to educate and advocate to public and peers about PD, and that it would be crucial to her emotional recovery to connect with people living with PD, both to learn from their lessons in coping and continuing to live creatively, and to offer comfort and compassion through music as long as she was able.

Methods: Griffith continued working as a PT for five years after diagnosis, but then found the PD related changes made continued work unfeasible. She retired in 2003, but has continued speaking out in hope of raising public consciousness and sensitivity about living with PD and other disabilities at her performances, providing public education.

Ms. Griffith had acquired a large and loyal following among folk music fans; they have proven to be supportive of her use of her musical performances as an opportunity to speak out on the subject of living with PD.

She has presented programs for PD related gatherings throughout the US and Canada. Often she concludes a didactic presentation with a musical performance; her presentations have been described as inspirational.

Results/Outcomes: Griffith's aim has been to increase public and peer awareness about PD, thereby dissipating prejudice and isolation. Her quest is ongoing.



Educational and Awareness Raising Programs

LWP1.11

Simulation Based on an Unfolding Case Study "Living with Parkinson's Disease: An American Experience"

McCormick, M

Towson University, United States

Background: To prepare the next generation of health care providers, educators are asked to examine current content and pedagogies to ensure safe, quality, culturally competent care. Student nurses are interested in learning that enhances their knowledge with "real world" examples so that they can develop leadership skills which can be transferred to the workplace.

Aims/Objectives: In order to assist educators in designing clinical learning approaches, simulation based on an unfolding case study can mimic reality without compromising patient care. It can help the learner analyze and reflect on how leadership skills can be incorporated into daily practice. During nursing students' basic undergraduate education, they typically care for only one patient at a time in the hospital or community setting. However, this limited experience may provide students with little or no exposure to the systems that impact health care and quality. This pilot project would test and evaluate a program called "Living with Parkinson's".

Methods: This program employs an unfolding case study approach with five characters living in a household while caring for a family member suffering with Parkinson's. During the semester, students have assignments related to the virtual case studies about the family's daily struggle with caring for a patient with Parkinson's.

Results/Outcomes: This dynamic family situation increases student awareness and sensitivity about family and patient issues and may provide suggestions for improving learning about taking a leadership role in the care and management of Parkinson's disease.

Discussion/Conclusion: Students brainstorm to answer the questions about nursing care and management as the case study unfolds and respond to realistic challenges regarding activity, sleep and finances, medication and available community resources which are woven throughout the case study. This program recognizes the emerging role of nurses as leaders in the American health care delivery of patients with Parkinson's disease.

LWP1.12

Facing the Future with Parkinson's

Dixon, M

Parkinson's NSW Inc, Australia

This paper reports on an innovative program of Parkinson's NSW, the peak body providing information and support for people living with Parkinson's (PLWP) in NSW, Australia. The Facing the Future with Parkinson's program was shown to make a difference in the quality of life of PLWP. PLWP who had accessed our Counselling service and our established statewide support group network had identified anxiety about managing their future in a number of areas, including reduced mobility, worsening symptoms, social isolation and financial resources and estate planning. They also rated face-to-face seminars as a high priority in education delivery. The Facing the Future with Parkinson's program directly addressed these needs. The aim of the program was to: 1) provide information on living with Parkinson's disease and on appropriate planning for the future; 2) break down social isolation and offer support both at individual level by linking them to services such as our counseling and InfoLine as well as support via the support group network; and 3) offer long term support by providing each participant with an Info kit containing relevant information and linkage to specialised community services.

Method: The program was promoted through our *Stand by Me* newsletter, local radio and local papers and flyers to general practitioners and neurologists. The target group were people facing the future with Parkinson's, their partners or carers, including newly diagnosed or people who have had a diagnosis for a number of years. The program consisted of two half day information seminars in metropolitan areas; a one day seminar in 10 regional areas and 5 teleconferencing groups for people unable to attend. The number of participants recruited was 402. Funding for the project was obtained. Topics covered by the professional speakers included: Parkinson's disease symptoms and early treatment options; practical advice and community resources as aids to daily living challenges; information on enduring guardianship and power of attorney; and information on financial and estate planning. Each participant was invited to complete a Seminar Evaluation Form. The return rate was 70% percent (280).

Results: To the key question of Did The Information Gained From This Seminar Help You Face The Future With Parkinson's? 10 answered Maybe, and 270 answered in the positive. Examples of the wide range of specific comments on how the program was beneficial and ideas for future seminars will be discussed.



Educational and Awareness Raising Programs

LWP1.13

The Grassroots Effort to Make the PD Tulip the National Symbol for Parkinson's Awareness in the United States

Burns, JE
United States

Background: The United States (US) has six major national Parkinson's organizations, and several large independent regional organizations (orgs). Each has its own logo or symbol. But there is no one unifying symbol for Parkinson's disease (PD) Awareness.

Aim(s) / Objectives: To document the successful grassroots campaign to make the PD Tulip the national symbol for US PD awareness. In early 2007, Jean Burns met Karen Painter. Karen showed Jean her unique tulip design, with leaves that spelled "PD", and the dream for this to become the US symbol for PD Awareness was born. Jean promised Karen that she "would do everything in her power" to make this the symbol for US PD awareness. And in 2007, Jean began a grassroots campaign to promote the PD Tulip.

Discussion: The poster will document and provide examples of the steps that Jean Burns (and a handful of supporters) took in mounting a national grassroots campaign to make the PD Tulip the national symbol for US PD awareness. The campaign began in 2007 and continues to the present:

- by writing letters
- by using Internet
- by using social media
- by creating YouTube presentation
- by speaking at conferences
- by creating posters
- by implementing online petitions
- by emailing
- by funding and giving away pins
- by personally contacting leaders

Conclusion: By December 2009, four of the major US Parkinson's organizations have accepted the PD Tulip, and thousands of people with Parkinson's (PWP) across the US are wearing the PD Tulip pin, and using the PD Tulip. The dream is coming true.

LWP1.14

Parkinson's Outreach. Hope for Tomorrow. Help for Today
Robledo, I
United States

Background: This project evolved from talking to the many people with PD who could not afford health care and/or medications related to the disease. After several months of coming to terms with my Young Onset Parkinson's Disease diagnosis, I decided that I needed to do what I could, while I still could, to help as many people as possible. The motto was developed with the idea that we could provide the much-needed help locally and at the same time allow for the hope to hold on to as the work continues to find a cure, thus "Hope for Tomorrow. Help for Today". The program in and of itself helps to put a face to this disease because of my/our willingness to speak to whomever will listen to our story of living with PD and provides awareness, which leads to education, which in turn helps raise funds for our cause from those willing to join this ongoing effort.

Objective: The objective of Parkinson's Outreach is to provide resources for persons with PD by way of helping pay for physicians fees and/or medications that are directly related to PD, up to a maximum amount per year, depending on the availability of funds.

Methods: The method used for providing this assistance to persons with PD starts with a short application process, available through local neurologists that treat persons with PD or our organization directly. There is no income or resource limit but, subject to funds availability, a maximum cap is placed on a yearly basis. A second part of the process involves getting permission to research prescription assistance programs for which the person could qualify and providing referrals to these programs, thereby helping to keep more funds available locally for those that would not otherwise qualify for prescription assistance programs. It is the intent of the Parkinson's Outreach organization, a non-profit public charity, to seek grants for this specific-use program and use all of the grant money and/or donations to be given out in the form of monetary help to those in the local area living with PD. The longer-term goal will be to help increase clinical trial participation by reimbursing expenses related to clinical trial participation, with the ultimate goal of helping fill clinical trials quickly and finding answers sooner in the quest to find a cause and a cure for PD.

Conclusion: In the quest to help those less fortunate to get the help needed, we can relieve the burden of medical expenses that continue to increase for medications we cannot do without.



Educational and Awareness Raising Programs

LWP1.15

A Picture Can Make a Movement

Zikos, P; Berri, S; Zouroudis, D; Papatriantafylou, Y; Papageorgiou, K
EPIKOUROS kinisis, Greece

Background: In Greece awareness about Parkinson's is very low. EPIKOUROS – kinisis, the Greek non-profit organization for Parkinson's disease completed in December 2009 a photography contest. Its theme was "Akinesia and Movement". Patients living with Parkinson's are trying to find the golden mean between Akinesia and movement in every aspect of their life. This was the first pilot action of EPIKOUROS – kinisis.

Aim of the action: The aim of the contest was not only to raise awareness of Parkinson's disease but also to encourage volunteers to learn more about EPIKOUROS – kinisis and take part in its activities.

Methods: The contest took place through Facebook and the participants could upload their photos in the e-page, which was created especially for this purpose. The decision of using the internet for this purpose was taken because people that are isolated due to movement disorders can nowadays be in touch with the rest of the world through the internet. Also you do not need a budget to organize an action like that and make a success but only free time.

Results: Many people embraced this idea. Through Facebook we met two of the three members of the contest's committee; a photographer and an Assistant Professor of fine Arts of University of Thessaloniki. Also many people reached us to help the future actions of EPIKOUROS – kinisis.

The winner of the contest was Ms. Monika Kritikou, photographer, who managed to create a photo in which the harmonious movement of a classical ballet dancer is combined with the tulip, the Parkinson's disease symbol. The second prize went to Mr. Dimitris Mavropoulos. His photo depicts graffiti but at the same time a way of living under the message "Life not just Survival". Last but not least, Mr. Ilias Kontogiannis won the third prize with a photo on which he captured the movement of a falling petal. The winning picture will be used in our activities for this year.

Discussion: This contest gave rise not only to extended discussions on Parkinson's disease but also motivated people to volunteer, to approach our organization and share with us their ideas. But above all the most important thing was that people with PD felt that they are not alone any more. Now, in Greece, we can go a step further.

LWP1.16

Parkinson Partners: Coordinate Local Resources for Best Care

Sutherland, DP; Sutherland, DT
Neuro Challenge Foundation, United States

Background: In the U.S., treatment of Parkinson's disease (PD) has traditionally been oriented toward physicians and pharmaceuticals. Patients present to the physician and are prescribed medication and, hopefully, rehabilitation. The remainder of treatment options and issues are left up to the discretion and investigatory capacities of the patient and caregiver, who are often limited in their ability to fill in this gap. Services that are usually not provided include transportation, exercise programs, alternative / integrative treatments such as Tai Chi or Yoga, access to research studies, long-term care planning, personal and marriage counseling, neuropsychological evaluation, healthcare attorney access, and financial advice, just to name a few.

Aim: To expand and enhance care of Parkinson patients and families

Methods: Working with our local hospital and practitioners, we developed a community-wide program (Parkinson Partners) to provide comprehensive, inclusive, free care for PD patients and their families in a multi-county area in SouthWest Florida. There are several key components. The first is an extensive resource database identifying a variety of community practitioners and providers who are trained / approved by our team. The second is a dedicated patient advisor who acts as an assessor, educator, and resource for each patient / family at the request of any local physician. The third is our local hospital, which has provided space and, via its associated foundation, funding for this program. The final component is the Board of our local Neuro Challenge Foundation, which originated this idea and works to maintain the program.

Results: In practice, PD patients are referred by any local physician to Parkinson Partners, meet with the advisor, and get a very comprehensive, individualized "roadmap" of recommended resources, practitioners, facilities, websites, symposia, support groups, and more. Follow-up contact is made later to assess carry-through by the patient and new or additional needs.

Discussion: We believe our program is unique in its bottom-up approach to local PD care. No other organization in our area has the experience in resource evaluation or the demonstrated ability to join physicians, community resources, hospitals, patients and caregivers together in a unified effort to ease the burden of living with Parkinson's disease using one-on-one education at all stages of the disease.



Government Advocacy / Campaigns / Public Policy

LWP2.01

Life with Parkinson's Awareness Campaign

Lindvall, S; Graham, L; Browne, K

European Parkinson's Disease Association, United Kingdom

Background: In August 2008 the European Parkinson's Disease Association (EPDA) launched its Awareness campaign in English, focussing on the social and economic burden of late stages of the disease.

Aim: To raise awareness of Parkinson's and its impact by preparing materials on early and late disease management and non-motor symptoms; highlighting that with improved management, quality of life is improved and social and economic costs are reduced.

Objectives:

- Highlight the challenges experienced by people with Parkinson's
- Raise awareness of the consequences for daily living
- Influence stakeholders
- Raise funds for resources, management and research projects. **Methods:** Personal stories by people with Parkinson's from many countries were linked to facts explaining different symptoms, the affect on the family; medical treatment; European incidence and prevalence; indications and contraindications; cost of treatment and care; treatment aspects and side effects. "Life with Parkinson's" booklet and DVD were the campaign tools.

Results: "Life with Parkinson's" translated into Greek, Norwegian, Romanian and Swedish were launched on World PD Day 2009. In June the importance of early diagnosis and treatment to delay disease progression was included and translated into French, German, Italian, Spanish and Turkish. The EPDA conference launched the Hungarian version forming a major part of the national organisation's awareness campaign. By the end of 2010 nineteen international languages will be available. The awareness campaign was shortlisted in the 2009 European Excellence Awards.

"Life with Parkinson's - non-motor symptoms" will be launched alongside the World Parkinson Congress.

The Awareness Campaign is supported by numerous international neurological associations, healthcare professionals and treatment industry www.parkinsonsawareness.eu.com/

Conclusions: Support for the campaign and its materials highlights the importance of providing tools to assist national organisations in raising awareness of the social and economic cost of managing Parkinson's in Europe.

LWP2.02

Awareness of the Need for More Focused Research into Parkinson's Disease

Lindvall, S; Skoog, K-G

Swedish Parkinson's Disease Association/ParkinsonFörbundet, Sweden

Background: There is a great need to communicate Parkinson's disease research results so that they become understandable. More and more people should support research so that results move faster from "bench to bed" in order to improve quality of life for people who are suffering. People in general and decision makers in particular are not committed enough. Because the disease develops over many years it could therefore be construed that there is no urgency.

Aim/Objectives: To create awareness among decision makers and the general public about the physical and emotional impact of Parkinson's and the need for more research, in order to increase funding for Parkinson's research. **Methods:** As a result of the ongoing EPDA Awareness campaign in Sweden, the translated version of 'Life with Parkinson's', was sent to thousands of decision makers by the Swedish Parkinson's Disease Association on World Parkinson's Day 2009. Together with an illustrative DVD, awareness was raised concerning the need for more focused funding of research into Parkinson's disease. A research seminar was arranged in Lund, one of Sweden's the most important research centres, the focus being the Swedish Parkinson Academy. Her Majesty Queen Silvia of Sweden participated as protector of the Swedish Parkinson Foundation.

Results: As a result of the seminar and the awareness campaign, the amount of funding for the Swedish Parkinson Foundation has increased and new contacts have been made with decision makers and politicians.

Conclusions: To create awareness by providing information improves the perception of decision makers and general public for the needs of people living with Parkinson's disease creating an increased willingness to actively support research within this field.



Government Advocacy / Campaigns / Public Policy

LWP2.03

www.parkinsonsmovement.org – A Hub for the Parkinson's Community
Stamford, J A & The Cure Parkinson's Trust Patient Advisory Group
United Kingdom

Background: There are several Parkinson's disease (PD) discussion fora on the Internet. For the most part, these are vehicles for discussion among PD patients (PwPs). Subjects include treatments, adverse events, and related aspects of disease management and patient care. Discussion threads in these fora are predominantly instigated by individuals and reflect their personal concerns. Typically these are seeking answers to specific questions about their PD management. Despite the popularity of these online fora, there is comparatively little interaction between pharmaceutical, medical and patient groups. The fora reflect individuality rather than collectivity.

It is for this reason that www.ParkinsonsMovement.org has been created. Run by people with Parkinson's, and led by the Parkinson's Advocate Group, it is designed to gather opinion, to inform opinion formers and to galvanise the Parkinson's community.

Aims / Objectives / Methods: www.ParkinsonsMovement.org is predicated on the view that, of all individuals and groups involved with PD, PwPs are the best equipped to comment on current and future issues. The purpose of the hub is to harness the best aspects of the fora (large numbers of patients, popularity, and rapid responsiveness) and to integrate these aspects into a vehicle for information gathering, dissemination, and lobbying.

The objectives for www.ParkinsonsMovement.org are to provide an interactive online "hub" for PwPs. The hub will (a) gather information through polling (e.g. priorities for research, side-effects needing urgent redress, commonality of symptoms, similarities of diagnosis, care-related issues), (b) communicate findings to government, media, opinion formers, industry and the PD community (PwPs, their carers, their families, healthcare professionals, researchers, industry), (c) provide regular and insightful coverage on research breakthroughs and (d) encourage increased traffic.

The hub's aims and objectives will be operationalised by (a) creating at least one survey per month to generate interest, (b) identification of key issues for PwPs, (c) carefully orchestrated campaigns to draw attention to these issues, through www.Parkinsonsmovement.org, by lobbying, a consumer media campaign, and online campaigns.

Results / Discussion: The website has been created and the first surveys designed. The site will go live shortly and by WPC 2010 there will be further feedback available.





Living Healthier with PD

LWP3.01

Partnering with a Community-Based Agency to Develop a Comprehensive Parkinson's Wellness Program

Gonzalez-Ramos, G¹; Di Rocco, A¹; Lemen, A¹; Cohen, E¹; Rossi, R²

¹NYU Parkinson and Movement Disorders Center, United States; ²United States

"This program has given me back a sense of control over my body. I hated exercise before - now I'm going to classes 4 times a week and loving it . . . I went from victim to victor". - Rande G., program participant

Background: The New York University Parkinson (NYU) and Movement Disorders (NYU-PMD) Center has formed a unique partnership with the Jewish Community Center (JCC) in Manhattan to develop a comprehensive, Parkinson's-specific wellness program for persons with Parkinson's and their families.

Aims / Objectives: The program has remained in high demand since its inception and its success is building the energy for growth. Starting with three fitness classes, the program has identified needs through an ongoing dialogue with the community and now includes classes in tai chi, Pilates, yoga, NIA: movement and music, chair exercise, water exercise and the Alexander Technique, as well as education and creativity events and a psycho-educational support group for caregivers.

Methods: The shared knowledge of the two founding institutions provides the expertise needed for a safe and welcoming hub for the Parkinson's community and the continuing exchange of expertise greatly enhances a dynamic definition of the existing and changing needs of its participants. All program staff and instructors are well educated in working with persons with Parkinson's and their families. This training includes the National Parkinson Foundation's Allied Team Training for Parkinson program, as well as ongoing in-service education and seasonal team meetings with Parkinson's healthcare professionals from the NYU-PMD Center.

Results: This partnership between a medical institution and a vibrant, community activity hub broadens the borders of access to specialized care for its participants and is impacting their lives on a day to day basis by providing proactive opportunities that complement their medical care.

Discussion: This poster will show in graphics and narrative the growth, scope and development of this popular and replicable program.

LWP3.02

The Layne Library, Using Social Networking to Improve the Lives of Parkinson's Patients

Bernard, CB¹; Layne, RB¹; Gupta, A²

¹The Layne Library, United States; ²UCSD, United States

Background: When Bruce Layne was diagnosed with Parkinson's disease over ten years ago, he found it quite difficult to find helpful information and local services. As time as passed, he found there was a proliferation of information online, but no one central place that he could trust and visit on a daily basis to find up to date information on the disease, ways he could be involved both locally and internationally, and other tools that were becoming available but that he often had to either wade through google searches to find or hear about through friends.

Aims / Objectives: The goal of the Layne Library is to be an online (and off-line) collaborative Parkinson's community where all Parkinson's stakeholders including other Parkinson's non-profits can share tips, keep up with the latest news and become empowered to actively participate in helping researchers find the cure through our curated online Parkinson's portal and through the sharing of their own Parkinson's experiences to be mined for the benefit of researchers everywhere (with privacy controls in place).

Method: We will create a Parkinson's specific social networking site with access to a suite of tools including debate forums, patient and caregiver reporting and tracking, fun and informative videos and other interactive content including online casual gaming.

Results: We hope that through increased sharing of content, ideas, services and experiences, Parkinson's patients and caregivers will experience an improved quality of life, and PD researchers, doctors and students will have a larger and more available pool of helpful information, statistics and volunteers from which to gather information and support.

Discussion: As we are in the formative stages of development, there are no details yet on the outcome of our program, but as more and more boomers continue to spend more and more time online, we are confident that this Parkinson's portal will play a helpful and important part in all Parkinson's stakeholder's journey.



Living Healthier with PD

LWP3.03

Faster, Longer and Stronger

Kancilija Staničič, A
Slovenia

Given the existing literature reviewed, in Slovenia we do not have enough suitable and good literature in Slovenian language, which would correspond to our patients. A lot of good literature that is suitable for patients is written in English. Our patients are elderly and the majority of them do not understand English, so we decided to prepare a guide for them to improve their quality of life and to help the patient's caregivers.

The manual contains exercises that are suited for patients with Parkinson's disease. The exercises are described and accompanied by photographs. Exercises are presented in prone, lateral, four-legged position, sitting and standing. The manual contains exercises for fine motor skills and facial muscles.

Chapter Two is devoted to bradykinesia and freezing. This chapter contains helpful tips on how to prevent freezing, and how to safely turn without freezing.

Chapter Three is devoted to one of the biggest problems many of our patients face - falls. This section describes how to prevent patient falls and what can be done after the falls. Steps that teach how to get up from the floor are equipped with photos.

Chapter Four describes how can patients learn how to move from a lying position in bed to safely sit on the edge of the bed. All steps are presented with photographs.

Chapter Five is devoted to caregivers. In this chapter caregivers can learn step by step the easiest and most secure way to help transfer the patient from bed to wheelchair. The manual is written in the hope for a better quality of life for our patients, in the hope of a better tomorrow. Now let's go "Faster, longer and stronger".

LWP3.04

"Think Big" and "Feel Big" with Parkinson's Disease

Lif Kimchi, O; Tamir, R; Pessach, L
Meir Medical Center, Kfar Saba, Israel

This article describes group intervention with Parkinson patients in the Meir Medical Center, Kfar Saba. The group consisted of 13 Parkinson male patients, average age of 66 years, diagnosed more than 10 years. Nine of the patients were stages 3-4 and four, in stage 2, according to the Hoehn-Yahr (1967) rating scale, classifying functional impairments and disability. The weekly treatments, guided by a multi-disciplinary team of physiotherapist, social worker and occupational therapist. Refers to motoric aspects as well as functional and supportive ones.

The two years therapeutic intervention was made in light of the "Think Big and Feel Big with Parkinson". In the motoric functional area, the "Think Big" approach, for Parkinson patients, was used.

This method focuses on improvement movement amplitude, thus increases its speed. Treatment is based on terms of motor learning principles and focus on integrating and practicing to daily life activities. These principles, allow this approach to be applicable and suitable in occupational therapy and physiotherapy treatments with Parkinson patients.

In the supportive area, the "Think Big" approach was expanded to "Feel Big". "Feel Big" relates to the positive powers amplitude in a person. The therapeutic rationale was to empower the individual and the group. It was translated to group activities, with two objectives. The first, was each group member made a presentation of himself in various means and ways, focusing on his areas of interest, living with Parkinson disease. Each member presentation required significant cognitive, social, emotional and physical capabilities. The second objective was to edit a movie clip reflecting the group processing during the two years period (the clip is 14 min. long and fully translated to English). The therapeutic intervention contribution was measured in an experiential way, based on the members feedback. It was described as contributing to functioning, challenging and empowering the sense of capabilities and self esteem. Based on the outcome, it is recommended to consider implementing such intervention with other therapeutic groups, in various ages and places and test its value add in addition to the structured tools, currently used.

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Living Healthier with PD

LWP3.05

Beyond Medication: An Integral Rehabilitation Program for Patients with Parkinson's Disease

Moreira, HBT; Costa, AR; Martins, FC; Marques, JM; Ferreira, LS; Kummer, W; Alves, PG; Paranhos, T; Verissimo, MV; Barbosa, AP
The Sarah Network of Rehabilitation Hospitals, Brazil

Background: Many Parkinson's disease patients are still labor active and still have an important role in their families at the disease onset. After the diagnosis there is a decline in the social functioning. The majority of rehabilitation studies in PD patients are focused to one dimension of the symptoms, usually in patients with more advanced disease, while none so far have described an integral approach to rehabilitation in the outpatient setting.

Aim: Considering the multidimensional health-related aspects of the quality of life we have set up a specific interdisciplinary rehabilitation team for PD patients. The objectives are to inform and to implement measures to reduce the impact of the disease. To keep these patients' labor and social activity levels up is the ultimate goal.

Methods: The activities were divided in informative and participative sections. In the former facts about the disease and specific themes such as managing the medication, the use of social resources and perspectives for the treatment are presented to the patients.

In the participative section, the patients were invited to participate in physical activities which involved exercises in water, coordination and cardiovascular conditioning. Context-based activities such as painting, clay molding, and games were also developed. In each of these activities a specific aspect was emphasized such as games for speech and painting for perceptual and attention training. At this time, the patients also attended groups to help with coping strategies.

Results: So far 20 patients were included and attended our center twice a week during four months and monthly after. The patients were subjected to evaluation of medical, cognitive, physical and social aspects. The age at admission was 66.9(±9.4, range 43-79) years, the duration of symptoms was 4.5(±2.6, range 1-10) years and the Hoehn and Yahr staging was 1.9(±0.2, range 1.5-2.5), the follow-up was 11.5(±2.6, range 9-14) months. All patients were on medications to treat PD symptoms.

The overall attendance rate was high and the perception among the patients was that the program was very rewarding. At the inception the patients were engaged in 2(±1.4, range 1-6) physical and 2(±1.4, range 0-5) extra-domestic occupational activities. The same was seen at the last follow up visit.

Conclusion: An integral program for rehabilitation in PD outpatients may be an effective measure beyond medication to maintain social function.

LWP3.06

How the Power And Safety Of Water Helps People Cope With Parkinson's Disease

Williams, DT
United Kingdom

Background: It is widely accepted that people with Parkinson's benefit from regular exercise. This poster argues the case for doing warm-up, stretch, balance and aerobic exercise in water, in other words - hydrotherapy.

Aims: Hydrotherapy provides a safe, warm environment where the patient can move either with the assistance of the water or against the resistance of the water. Water movement also constantly challenges balance and core stability.

Methods: Hydrotherapy is not simply swimming or walking up and down a pool. To get the maximum benefit, it is recommended that the start point is one to one sessions with a trained hydrotherapist or qualified assistant. This involves a personal assessment and then the design of an appropriate programme of exercises. The hydrotherapist will explain the purpose of each exercise and what specific muscles are being targeted. Depending on the patient's circumstances, it is often possible that these exercises can then be carried out by the patient on their own, following the plan and programme that has been designed for them. It is important to review progress and adjust the programme periodically with the hydrotherapist.

Results and discussion: The benefits of water include:

- Warmth to decrease muscle tightness and general stiffness
- Decreased weight bearing due to the buoyancy of the water
- Support from the water to prevent falling and injury
- Improved blood circulation
- Resistance to increase exertion without aggravating arthritis or other similar health problems.

This poster will cover the following:

- Author's personal experience of hydrotherapy
- Photos of the author "before" and "after" hydrotherapy

A description of the types of exercise:

- Walking, cardio in deep end, balance exercises
- Differences between land vs water exercises



Living Healthier with PD

LWP3.07

S.O.S – Electronic Passport for People with Parkinson's
Raicu, D
Romania

I created the device because similar models on the international market are difficult to use. It is an automatization of the international Parkinson's Passport launched by the European Parkinson's Disease Association, which can be found on the website <http://www.epda.eu.com/> The device is currently in process of patenting at OSIM (State Office for Inventions and Trademarks), as unique trademark.

The device is meant both for ill and healthy people, who are in an extreme situation after being involved in an accident or a natural catastrophe. The device is triggered by pushing a button and offers information about the respective person (name, age, medical affections, residence, close persons, family physician and their telephone numbers) through an audio message. The device is accompanied by a laminated card on which some of the above mentioned information is written. The device can be integrated in a cell-phone, in which a special key can trigger the recorded message and call some programmed telephone numbers.

As a matter of fact, in some country there is the SOS message service, an option triggered by pressing the volume key four times. Until now no telephone operator has introduced this service in Romania. Both on the device and the card a visible red rhomb – the international symbol of PROTECTION – is drawn. During the creation process international standards and civil society demands were taken into consideration.

LWP3.08

Dream! Act! Live! Life After Diagnosis: How To Live Your Best Life Now!
Bischoff, T
United States

Background: Todd Bischoff is a motivational and inspirational speaker currently living with Young-Onset Parkinson's Disease. Todd uses past challenges from his personal life – child abuse, runaway, drug addiction, alcoholism, homelessness, severe lower back injury, PTSD, intense migraine headaches, and major hearing loss – to encourage others to find the strength from within and use their own past challenges to live their best life now while dealing with Parkinson's Disease. As a former athlete, actor, radio personality, Certified Child Life Specialist, and currently an Adjunct Professor in the Education Department at a private university, Todd uses those tools to deliver a polished, personal, humorous, and highly informational presentation suitable for people with Parkinson's of all ages, their caregivers, friends, and family.

Aims / Objectives: To empower people with Parkinson's, their caregivers, families, and friends, to use their own power from within, while following some simple and easy to follow guidelines, so that they may live their best life now, even when dealing with a disease such as Parkinson's.

Methods: Todd uses a polished Keynote presentation created on a Mac, to deliver his personal message, touching each member of the audience with experiences that they can relate to on a highly personal level. Todd uses deeply personal stories and reflections from his life, integrating humor and thought-provoking ideas to inspire the audience to take control of their personal situation.

Results: The audience will leave empowered with tools to improve their lives and discover how to use their own strength to battle against Parkinson's while maintaining a healthy and active lifestyle and outlook on life.

Conclusion: People with Parkinson's need science, medication, and quality care in order to battle their personal version of this disease. But they also need to learn how to utilize their own inner strengths and take personal control, which can be overwhelming to many. They need motivation, inspiration, and most importantly hope! Todd will deliver simple, easy to follow guidelines mixed with his own personal experiences to illustrate his points, so that the audience can live their best life now!

For reference, please see www.ToddBischoff.com, especially the Biography page, the Story page, and the Testimonial page.



WORLD PARKINSON CONGRESS

Living Healthier with PD

LWP3.09

How Team Parkinson Helps PD Patients Achieve a Better Quality of Life

Bali, JG

Parent organization: The Parkinson Alliance, United States

Background: Team Parkinson was formed in 1999 by a group of PD patients, caregivers and medical professionals to raise awareness and funding for research. After two successful events, a third goal was added: to empower PD patients to take charge of their condition through goal setting, exercise, and teamwork.

Objectives: Team Parkinson aims to engage PD patients, caregivers and medical professionals in the shared objectives of raising awareness in the community, raising funding for scientific research toward a cure, and giving patients the tools, and the inspiration needed to take control of their own condition and improve the quality of their lives.

Methods: The primary vehicle for achieving these objectives is through targeted goal-setting and exercise programs specifically focused on walking, running, and bicycling. Team Parkinson has been an official charity of the Los Angeles Marathon since 2000, and the San Francisco Marathon since 2005. Using these major events to establish reasonable short-term goals helps patients, caregivers and treatment providers the opportunity to raise awareness and funding, and gives patients the specific training necessary to create long-term habits of self-discipline and better lifestyle choices.

Results: Since 2000, Team Parkinson has participated in many events from patient conferences to sporting events either as a team, or as individual participants representing the Team. The Team has been represented in Australia, Japan, China, Norway, Brazil, and Austria as well as in most major running events in the US. It has provided a platform for discussions at support groups and patient conferences, and has directly funded research on brain plasticity through exercise interventions (USC).

Discussion: Marathon training is a particularly strong motivational tool and inspirational example of patient-managed improvements to quality of life. Through its training programs, the Team has helped more than 25 Parkinson's patients to complete a full 26.2 mile marathon, and many hundreds to complete a 5k walk or run. In its brief 10 year history, Team Parkinson has raised nearly \$2 million (USD) for research and has funded grants at major Parkinson's research centers.

LWP3.10

Every Victory Counts: A Patient Care Program Offering Inspiration and Self Care Support for Living Well with Parkinson's Disease

Howard, A¹; Farris, SM¹; Giroux, ML²

¹United States; ²Evergreen Hospital Medical Center, United States

Background: There is limited guidance to help the clinician and patient enhance self-care in the clinic and home despite its critical role in optimizing care (Wagner, 2002). As clinicians, we cannot expect that a treatment or education on lifestyle (ie. nutrition, exercise) will lead to positive change. In fact, education alone can sometimes worsen sense of wellbeing (Ward 2004). Studies highlight the need for tools that incorporate lay language and concerns, focus on individual priorities and motivational steps for positive change, offer concrete steps for action, and are easy to use (Kennedy 2002). These tools must be easy to use in clinical settings as well as the home and engage patient, family and clinicians in the process.

Aim: Develop a Parkinson's patient tool to engage patient and clinician in self-care leading to positive change.

Method/Program Description: We partnered with the Davis Phinney Foundation to develop, Every Victory Counts™: An essential guide to living well with Parkinson's. Program includes: 1) interactive self-care manual; 2) inspirational DVDs; 3) online updates and community (blog); 4) clinician education on motivational change, patient engagement. Content was shaped by feedback from over 50 PWP collected via survey, focus groups, and interviews.

Results: The manual is the program cornerstone featuring: 1) designed for use during and between appointments; 2) designed to be used as an integral component of patient care; 3) takes a holistic approach to care and empowers patients to improve their quality of life; 4) can be updated with materials or personalized to reflect patient's priorities (updates and patient management tools available online); 5) layout is visually engaging to encourage dialogue with family and friends.

Four critical QOL themes were included.

1. Education
 - Content in non-medical language.
 - Written with emphasis on positive change today.
 - Principles of self-care management.
2. Inspiration and Motivation as told by people with Parkinson's. This connection with a greater community was identified as very important in overcoming feelings of inertia and hopelessness.
3. Self-care Worksheets to identify areas of concern, facilitate communicate with healthcare team, and create personal action plans to address them.
4. Self-care and Clinical Care Section - Use during and between clinic appointments.

Table of Contents

Introduction	How to get the most from manual?
What you need to know about Parkinson's	Disease Overview, Symptoms
Living Well Now	General Health, Wellbeing, Mmedical, Nonmedical and Surgical Treatment, and QOL
Parkinson's Insider's Perspective	Lessons from PWP
Worksheets	Symptom self-management
Clinical Appointments and Homework	Goal Setting, Preparation and Organization
Resources	Resources

Information is available at: www.everyvictorycounts.org



Living Healthier with PD

LWP3.11

The Parkinson's Self Assessment Tool

Matthews, H¹; Ashton, J²; Heisters, D³

¹The Cure Parkinson's Trust; ²GSK, United Kingdom; ³Parkinson's UK, United Kingdom

Background: "By people becoming more aware of their health, they become more interested and engaged in their condition, providing a sense of control. And control is key in Parkinson's", Tom Isaacs, a person with Parkinson's.

Aims: As identified in the "Make Every Appointment Count Survey" October 2009, there is a need to improve communication between patient and clinician during valuable appointment times

- To encourage an individual to identify and highlight traits within their own condition
- To provide additional information on the overall pattern of an individual's Parkinson's and its changeability
- To be useful for clinicians and contribute to overall treatment plans

Methods:

- The brainchild of people with Parkinson's
- Developed, tested and evaluated by experts: people with Parkinson's and healthcare professionals.
- Currently being piloted in three centres in the UK: Hull, Derby and Southampton
- Created and distributed by The Cure Parkinson's Trust
- Championed and distributed by Parkinson's UK
- Funded by GSK as a Service to Medicine

How does the Parkinson's Self Assessment Tool Work?

- Choose something that is relevant and meaningful. It could be walking a certain distance, or a domestic chore such as unloading the dishwasher, or it could be climbing the stairs, or ability to type a sentence. The key thing is that the activity or task is a part of everyday life and the tool is easy to complete.
- Next, monitor the activity or task every day for two weeks leading up to the next appointment
- Keep a record of other points such as sleep patterns
- Make a list of other points to raise in the appointment
- Take the tool to the next appointment and discuss with the Parkinson's Healthcare Team

Steering Committee: Comprising Parkinson's specialists nurses, physiotherapists and occupational health specialists, measurement experts, patients, The Cure Parkinson's Trust, Parkinson's UK and GSK.

Results and conclusion: Pilot study will be completed by the end of May 2010 with the results and final tool ready for presentation at WPC 2010.

LWP3.12

Parkinson's Stepping Forward: Salsa and the Benefits of Dance

Côté, D¹; Tano, NB²; Rowat, KM²; Grimes, DA¹

¹The Ottawa Hospital - Civic Campus, Canada; ²Canada

Background: As there is no cure for Parkinson's and current medications have many limitations, alternative therapies have increasingly played a role in improving an affected individual's quality of life. Parkinson's disease is not only a movement disorder it is also a quality of life disorder that may lead to patients feeling increasingly isolated and self conscious as the disease progresses. Within the past decade there has been a proliferation in the use of dance and music activities as treatment modalities for those living with Parkinson's disease.

Objective: To promote health and a better quality of life by introducing Parkinson's disease individuals to the physical, psychological and mental benefits of music and dance.

Methods: The Parkinson Stepping Forward (PSF) Salsa group in Ottawa, Canada, has as its focus connecting emotions with motion. The program works in three ways: first, by offering the physical aspect of the program i.e. exercise involved; second, by improving concentration skills and cognition by learning and focusing on performing the new steps and sequences needed for the dances; and third by providing opportunities for socialization and improving relationships with partner or caregiver. PSF Salsa Ottawa is currently assessing the effectiveness of this program both the physical and social benefits, through PDQ - 39 questionnaires distributed to its members every three months.

Discussion: Dance and music therapy serves the important function by not only providing exercise to patients and their families but also enables them to feel engaged and "part of this world". PSF Salsa was started ten months ago and currently has 40 members who meet for two hours each Saturday morning. Parkinson's members are encouraged to do the activity with their caregiver and/or family members. Salsa classes are given by a qualified dance instructor, dance volunteers including the co-founder; a Parkinson's clinic nurse.

Outcomes: One year follow up data and more in-depth description of the program will be presented at meeting.



Living Healthier with PD

LWP3.13

Creating a Specialist Speech and Language Therapy Service for People with PD in East Dorset: Making a Difference

Owens, S¹; Reynolds, H¹; Amar, K²

¹Royal Bournemouth and Christchurch Hospitals, United Kingdom;

²United Kingdom

Background: Prior to 2007, people with Parkinson's disease (PD) in the Bournemouth area (approximately 900) had poor access to Speech and Language Therapy (SALT) with waiting lists of over 6 months for voice therapies and a limited range of interventions. With help from the Parkinson's Disease Society UK, the Royal Bournemouth and Christchurch Foundation Trust appointed a dedicated Speech and Language Therapy post for patients with PD (SALT-PD).

Method: Health professionals, volunteers, patients, and carer stakeholders were involved in designing an evidence based service to fit local need. Service aims included SALT involvement from early self management through to palliation for both communication and dysphagia. A full time post was skill-mixed between a lead PD-SALT clinician and three other SALTs to optimise succession planning, leave cover and a range of interventions. This included; group and individual therapies both at hospital and home, Lee Silverman Voice Therapy (LSVT), education forums, telephone reviews, and information leaflets. MDT working and a patient database to track involvement were also implemented.

Results: In spite of an increased referral rate of greater than 100% since the introduction of the service, waiting times were reduced from over 6 months to less than four weeks. The increase is probably related to the positive patients experience and thus increased awareness among other health care professionals. Patient's satisfaction audit for SALT showed a 95% "good/excellent" response. Examples of patients' responses:

"You've given me the tools to work at it and the weapons to fight it with"

"I never realised there was so much I could do to help myself"

"It's been like a party . . . completely invigorating"

Conclusions: A dedicated SALT-PD service is effective in delivering high quality and responsive care for PD patients throughout the course of the disease.

LWP3.14

European Parkinson's Disease Association (EPDA) Multilingual Website on Coping Strategies. Tricks Created by People with Parkinson's Disease

Graziano, M

EPDA Board Member, Luxembourg

Background: Many people with Parkinson's have discovered and developed strategies that help them maintain movement and improve mobility to overcome their personal obstacles on a daily basis. In 2007, EPDA launched an English Coping Strategies DVD and website, containing a catalogue of tips and tricks created by people with Parkinson's. In 2008, the DVD and website was presented at the 12th International Congress of Parkinson's Disease and Movement Disorders (1), resulting in many requests for translation in to different languages.

Aim: Translation of Coping Strategies DVD and website into several languages to reach a broader spectrum of people with Parkinson's in Europe and beyond.

Objectives: To share collected tricks and strategies developed by people with Parkinson's and their families while highlighting the importance of people's contribution to their disease management and demonstrating how people can learn from each other.

To provide professionals with strategies they can creatively apply during treatment and inspiring research in to how these tricks work and why.

Methods: Translation into Chinese, Dutch, French, German, Italian and Spanish.

Results: Creation of a multilingual website www.epda.eu.com/projects/coping-strategies-tips-and-tricks and DVD, being launched in Buenos Aires at the 14th International Congress of Parkinson's Disease and Movement Disorders as well as at a dedicated workshop for people with Parkinson's.

Conclusions: To educate people living with Parkinson around the globe to enable an improved quality of life, educational materials need to be produced in as many languages as possible.

1. "Coping strategies for motor fluctuations and dyskinesias developed by patients with PD and their carers" *Movement Disorders Vol 23 / Supplement 1, 2008,S339 P.1041*



Living Healthier with PD

LWP3.15

Painting with Parkinsons: Art as a Therapy for Parkinson's

Watson, C¹; Atkin, AL²; Knowles, S³; Aimers, N¹

¹Parkinson's Victoria, Australia; ²Person living with Parkinson's, Australia;

³Swinburne University of Technology, Australia

Background: While art has been used extensively for many years to help people cope with trauma, mental health issues and disabilities, the many varied and complex aspects of Parkinson's meant a different approach was needed.

Mrs Anne Atkin, an artist, art teacher and a person living with Parkinson's (PLWP), used her experience and knowledge to found 'Painting with Parkinson's' (PWP) in Victoria, Australia. With the support of Parkinson's Victoria, Anne runs a weekly program of PWP. She has also developed a workshop version of PWP which has been taken to Parkinson's Support Groups around Victoria. Anecdotal evidence from her PWP groups indicated that the program did increase confidence, take away isolation, improve mood and attitude and helped PLWP to realise that they were creative and did have an artist within.

PWP empowers, supports and best of all gives individuals the strength to fight to have a life with Parkinson's. Consequently, a vital step forward is to investigate and statistically document the impact of art as therapy for people with Parkinson's Disease.

Aim(s)/Objectives(s): To explore the impact of Painting with Parkinsons workshops over an eight week period on patient illness perception's, health outcomes (quality of life and psychological distress), levels of optimism and illness severity.

Methods: The study's questionnaire comprised of basic demographics, disease related questions and used established scales with sound psychometric properties to assess illness perception's, levels of anxiety and depression, quality of life, optimism and illness severity.

During attendance at the workshops, patients were asked to voluntarily participate in the present study at two different time points. Specifically, those who wished to participate were asked to complete the study questionnaire immediately after their first workshop session (time one) and then asked to complete the same questionnaire eight weeks later (time two). Importantly, a control group was utilised and were also required to complete the questionnaire.

Results: This project is still continuing and it is envisaged that by the time of the Congress, enough data will have been collected to start showing any trends.

Discussion: As the painting finished, the straight lines and edges told him what others had seen. His tremor had slowly disappeared and he had better control of his right hand and arm. Faces relax, tremors slow down and PLWP are finding a new way to cope with Parkinson's.

LWP3.16

Sleep Self Management Project – Scotland

Lynall, A

United Kingdom

Background: Out of the 10,000 people in Scotland living with Parkinson's it is estimated that 4,000 experience poor quality sleep, tiredness and fatigue. This single symptom has an enormous emotional and physical impact on all aspects of daily life. However, sleep problems feature very little in medical or other professional teaching, and people are often left to cope alone without support. When a person with Parkinson's is able to sleep, it becomes easier for them and their families to manage the other challenges of living with Parkinson's.

Approach: The sleep self management project developed following discussions between a range of stakeholders who identified a general lack of support and information about sleep. They highlighted the need to develop a non-pharmacological self management (SM) approach to sleep problems in partnership with people with Parkinson's. It was felt important that this support should be provided by organisations and individuals that have an understanding of and commitment to the principles of SM and by those able to reach people with Parkinson's.

Aim: The project aims to support people to improve their quality of sleep by;

- Working in partnership to support people to develop personalised SM for sleep problems - by training Parkinson's Disease Nurse Specialists, and AHPs with an interest in Parkinson's, as Sleep Counsellors
- Providing easily accessible, high quality self help material specifically aimed at Parkinson's disease and sleep.

Measurements and outcomes: As a result of this project, people report:

- Feeling more empowered and able to manage their sleep
- Improved sleep patterns and quality of life
- A sense of control over their sleep
- Having increased self efficacy to be able to manage sleep
- Improved ability and capacity to cope with little sleep
- Improved confidence of the tools to use to help manage their sleep
- Improvements to other area of their lives

This project started in October 2009 and will run until March 2011.



Living Healthier with PD

LWP3.17

Achieving the Impossible Together

Young, H¹; Dumitru, E²; Hernandez, AJ³

¹Center for Music Therapy, Inc., United States; ²United States; ³Team Dopamine, United States

Background: Parkinson's disease has a prominent feature of reduced mobility and slowness of movement. The sedentary habits that develop due to decreased mobility often lead to secondary life threatening cardiopulmonary issues. Leading researchers and physicians are increasingly recommending high levels of exercise to counteract these symptoms. Parkinson's patients at moderate to advanced stages of the disease are often left on the sidelines for sporting events and training programs which help motivate, safely train and encourage cardio exercise.

Aim(s)/Objective(s): To change the environment of fitness programs, events and trainings to facilitate Parkinson's patients of all levels to successfully participate.

Methods: The creation of Teams which use neurologically based training techniques for Parkinson's patients. Examples of techniques used are music therapy to improve timing and synchronization of movements and treadmills with harness support systems for indoor higher speed cardio training. Each team member has the goal to participate a minimum of two times yearly in a 10k event with the Team as a relay member. Each team member must agree to focus 60% or more of their thoughts on what they can do.

Results or Outcomes: Team I am/I can was formed in 2005.

In October of 2006, five people with moderate to advanced stages of Parkinson's disease successfully participated in their first 5k event. Since this time that Team has successfully competed in 11/10k events. The team size has grown to 40 participants incorporating those who have all stages of Parkinson's disease as well as other neurologic movement disorders.

Team Dopamine was formed for early onset Parkinson's disease? Many who were using walkers now use only canes or walking sticks. All have decreased the frequency of their falls. All have slowed the rapid decline of quality of life and decreased the prominence of the symptoms of their disease. The creation of these Teams has energized its team members to regularly exercise at a level that demands higher cardio performance.

Discussion: Although research supports exercise as beneficial to Parkinson's patients of all stages very little has been done to fund or organize fitness programs for Parkinson's patients. Most programs that do exist are targeted only to early stage patients. Team I am/I can provides a safe model to empower living healthier.

LWP3.18

Parkinson Wellness Recovery Network (PWR!NET™)

A model for delivering early and continuous access to neuroplasticity-principled exercise programming

Farley, BG; Stepan, K; Urquhart, M; Christenson, S; Nelson, M
United States

Background: People with neurological disorders can get better, yet traditional rehabilitation (standard-of care) and short-term therapy are simply not enough to fundamentally change brain function and slow motor deterioration. Early intervention programs for people with PD are not available despite the basic science research that suggests continuous access to the right exercise programs may slow or even reverse the degenerative process. Referrals to rehabilitation are typically made after functional impairments have progressed to the point of disability. Even when short-term therapy is available, the benefits of exercise quickly degrade unless adequate levels of continuous practice are maintained post-rehabilitation. The goal of PWR!NET is to increase the availability, quality, and standardization of neurorehabilitation and community neurofitness exercise programs that adhere to training principles shown in the basic and clinical science research to optimize function, learning, and brain change.

Methods: We propose to develop 1) PD-exercise expert training programs for the lay public, fitness professionals, and clinicians; 2) PWR!GYM™ sites that specialize in the coordination of neurorehab and neurofitness services, ongoing assessment, and that work with local PD-exercise experts to extend resources to remote areas; and 3) funding mechanisms to subsidize costs to participants. **Results:** We have acquired initial start-up funding and for the first PWR!GYM™ site and have been collecting data on feasibility (costs/adherence), and assessment data related to function, quality of life, fall/hospitalization/medication history every 3 months. To date, we have 40 members, one physical therapist and two trainers and offer 7 - 8 classes of varying intensities per week and customized 1:1 intensive training to address freezing and postural instability. We will summarize these data and report on our first educational programs and ability to acquire subsidies through local PD foundations and sponsors.

Discussion: It appears to be feasible to implement neuroplasticity-principled exercise approaches safely and with good adherence. Future studies are needed to determine if this delivery method is cost effective and effective in slowing motor deterioration.



LWP3.19

Examining the Potential of a Shared Education and Training Program to Increase the Psycho-Social Quality of Life in PWWs

Morgan, L¹; Todaro, V²; Hunter, C³

¹Mission Hospital, United States; ²Parkinson's Disease Foundation (PDF), United States; ³Baylor College of Medicine, United States

Background: The Parkinson's Disease Foundation's (PDF) Clinical Research Learning Institute (CRLI) is a three-day training that prepares people living with Parkinson's to serve as advocates within the clinical research process. To date, 68 individuals from across the nation have completed the program and are working within their communities as PDF Clinical Research Liaisons. In this role they engage in such activities as educating other people with PD about clinical research and study participation; serving on private and government review boards; and providing research sponsors and investigators with input on trial design, implementation and evaluation.

CRLI graduates have stated that the program has changed their lives; giving them the tools and confidence they need to be active in their communities and providing the opportunity to connect with like-minded individuals. Life satisfaction, motivation, self-esteem, perceived well-being and social interaction are important indicators of psycho-social quality of life among people with PD.

Objective: To determine if a program providing peer-to-peer interaction, knowledge sharing and skills building has the potential to influence the psycho-social quality of life in people with Parkinson's.

Methods: A survey will be administered to assess if there is a self-reported change in key psycho-social quality of life indicators among 2008 and 2009 Clinical Research Learning Institute graduates. Questions are being developed by referring to such instruments as de Boer's PDQL, Parkinson's Disease Quality of Life Questionnaire; PDQ-39 Questionnaire and the PDQUALIF, Parkinson's Disease Quality of Life Scale. Results will be collected, tabulated, analyzed and reported.

Results: Results will be reported.

Discussion: To date, CRLI graduates have provided anecdotal information that indicates a potential change in psycho-social quality of life due to their participation in the program. Past graduates have made such comments as "CRLI has energized my efforts to push the rock up the hill [deal with PD]"; "CRLI puts me in an information seeking and sharing mode rather than a helpless victim mode"; "an opportunity to become better informed about one's disease . . . is helpful in dealing with Parkinson's". This survey will attempt to quantify some of these influences within the context of psycho-social quality of life.





Influencing Research through Fundraising, Clinical Trials, Grassroots Campaigns

LWP4.01

Declaration of Clinical Rights and Responsibilities for People with Parkinson's

Burns, JE; Herman, LA; Jedlinski, S; Cohen, P; DeCamp, W; Planton, S; Stephenson, C; Willocks, P
United States

Background: Clinical research is essential to the development of new therapies and treatments for Parkinson's disease. Yet, due to a number of factors, including a lack of awareness and understanding of the research process, fewer than one percent of people with Parkinson's (PwP) in the U.S. participate. This is far below the number needed, delaying many promising trials. Those who do participate in clinical studies assume risk to help advance science through research, but are not always fully aware of their rights and responsibilities.

Aim(s)/Objectives: The intent of this document is to address the needs of all stakeholders in the clinical trial process by:

- Educating the Parkinson's community about the clinical research process.
- Empowering people with Parkinson's to make informed decisions about their clinical trial participation.
- Increasing participation and improving retention in clinical trials, helping to speed the evaluation and approval of new treatments.
- Providing a roadmap the research team can use to develop and conduct patient centered clinical research, which goes beyond existing federal regulations governing the informed consent process and adds patient rights that may not currently be common practice.
- Ultimately, inspiring a culture shift where the participant is viewed as a partner, not a passive subject in the clinical research process.

Methods: A group of patient advocates, facilitated by the Parkinson's Disease Foundation, researched this problem, interviewed clinical trial participants, and met for three years to write this document.

Discussion/Conclusion: This document has lain dormant for nearly two years. It has not been distributed to the scientific community.

We hope that by bringing this document to the WPC 2010 as a poster, it will open a dialog between the scientific community and patient advocates about the current clinical trials process in order to speed the the development of new therapies and treatments for Parkinson's disease.

LWP4.02

Patient Involvement in Parkinson's Research – 20 Years of SPRING

Hill, E; Holme, CA; Telford, JR
Parkinson's UK, United Kingdom

Background, Aims / Objectives: The Special Parkinson's Research INterest Group ('SPRING') was started in 1990 by members of Parkinson's UK whose objective was to accelerate the search for a cure.

Methods:

- (1) For two decades SPRING has been building links between the patient and the research communities, providing research information in lay language and promoting research focused on finding a cure. The magazine 'SPRING Times' has been published quarterly since 1995, and 'back numbers' posted on the SPRING website. SPRING has some 400 members from all walks of life, including retired medical professionals and scientists. All activities have been financed with funds raised by SPRING members.
- (2) SPRING's multidisciplinary research conferences, held biannually since 1999, have stimulated researchers to consider how their particular investigation fits in with the work of others and how an integrated picture of the whole disease process can be constructed. An example? The ground-breaking experimental surgical treatment with topical injection of GDNF was conceived at the first SPRING Conference.
- (3) In 2000 SPRING asked members to lobby MPs and peers, seeking their support for new legislation on the use of embryonic stem cells for medical research. The result? In six parliamentary debates (2000 - 2002) Parkinson's was mentioned over twice as often as any other illness. Despite heavy initial opposition the bill was ultimately approved by large majorities in both Houses of Parliament.
- (4) SPRING continues to identify opportunities for collaboration between researchers. In 2009 SPRING's international conference about the benefits of physical exercise addressed both scientific and practical aspects.

Conclusion: The above examples illustrate how a motivated patient group can, as part of Parkinson's UK, influence Parkinson's research and focus research strategies on finding a cure.



General Topics

LWP5.01

Rural Outreach Clinic in Rural Otago (New Zealand)
Ryan, PV
Otago Parkinsons Society, New Zealand

Background: People living far from major urban centres are often underserved populations. Rural Otago New Zealand covers a large isolated area that is often inaccessible during winter. Centralisation of services due to economic constraints often mean people with Parkinson's have to travel up to eight hours (return) to see their Neurologist. This is compounded by those who cannot drive and are reliant on families or friends who may not necessarily live close by. The impact of fatigue, discomfort, change of routine, financial cost and reliance on others are all indicators for stress and deterioration of symptoms Parkinson's disease. Local rural clinic health workers often do not have the specialist knowledge or understanding of the need for multidisciplinary assessment and continued care required for these clients.

Aims / Objectives: The Otago Parkinson's Society launched a new initiative aimed to improve access to and quality of care with an outcome of improved health outcomes for those in this rural area.

Methods: This poster identifies how multidisciplinary rural clinics consisting of; neuro-physiotherapist, speech therapist, occupational therapist, social worker and field officer were set up to ensure an adequate assessment of need occurred on an annual basis at a local area supported by regular home visits. This assured a quality PDQ39 and UPDRS assessment were completed in conjunction with a multidisciplinary consultation.

Results: The initiation of the clinic has since encouraged the local physiotherapist to provide a specialized weekly exercise class and improved networking amongst allied health workers.

Conclusion: The clinic has enabled the client and caregiver to attend a multidisciplinary meeting without the associated stress along with the opportunity to receive a holistic approach.

LWP5.02

Quality Criteria from the Patient's Perspective
van der Kolk, TA; Struikema, AJC
Dutch Parkinson's Disease Association, Netherlands

Background and Objective: Many health professionals develop and use guidelines for the treatment of and care for patients with neurological movement disorders. In addition to professional and scientific criteria, wishes and expectations concerning treatment and care from the patient's perspective are of equal importance. Therefore, Quality Criteria from the Patient's Perspective were developed in cooperation between two patient organisations: the Dutch Parkinson's Disease Association and the Dutch Association for Dystonia Patients. Firstly, these quality criteria can be used by health professionals to improve their treatment of and communication with patients. Secondly, the criteria raise awareness in patients about options in treatment and care by health professionals. Thirdly, they stimulate an active attitude of patients towards health professionals.

Methods and Results: A literature search was performed to select discussion themes. These themes were discussed in panels of patients and their relatives. From these panel discussions, two types of criteria were developed: 1) criteria for neurological movement disorders in general and 2) criteria for Parkinson's disease specifically. Some examples:

Criteria for neurological movement disorders in general:

- Health professionals are willing to learn from patient's experience with treatment and care of his disease.
- The neurologist informs the patient shortly after he has been diagnosed about the possibilities of multidisciplinary care. Main objectives of treatment and care are reduction of impairments and optimal quality of life.

Criteria for Parkinson's disease specifically:

- The neurologist informs the patient and his relatives about the possible effects of the prescribed medication. He does not only focus on (positive) physical effects, but also on the known physical, mental and behavioural side effects.
- The Parkinson's Disease Nurse Specialist coordinates the communication between all health professionals involved.

Conclusion: The Quality Criteria from the Patient's Perspective, developed by the Dutch Parkinson's Disease Association and the Dutch Association for Dystonia Patients, provide a useful tool for both health professionals and patients to improve treatment of, care for and communication with patients with neurological movement disorders in general and Parkinson's Disease in particular.



General Topics

LWP5.03

Reducing the Burden of Parkinson's Disease

Emr, M; Sieber, B-A

National Institute of Neurological Disorders and Stroke (NINDS), United States

Introduction: The National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health (NIH) and an agency of the United States government, is the nation's primary source of research funding for Parkinson's disease (PD) and other neurological disorders. The NINDS supports research studies that aim to reduce the burden of PD by improving the understanding, diagnosis and treatment of the disorder. The NINDS is committed to rapidly translating basic research findings into new therapies for PD. It also serves as an important source of information for people with PD and their families.

Methods: The Morris K. Udall Centers of Excellence for Parkinson's Disease support multidisciplinary basic, translational and clinical research at Centers across the country. The NINDS is currently funding several large, multicenter clinical studies, including the NET-PD study to test whether the supplement creatine can slow the progression of PD; a trial comparing sites of deep brain stimulation (DBS) for persons with advanced PD; and a study to determine whether CoEnzyme Q will improve PD treatment. The NINDS Parkinson's Disease Research Web, <http://www.ninds.nih.gov/research/parkinsonsweb/>, facilitates research efforts on Parkinson's disease and provides information for patients and caregivers. NINDS conducted recent strategic planning that will advance PD-related efforts.

The NINDS produces free educational materials and disseminates information about the disease via print and the internet. The Institute also provides outreach at meetings and timely news updates on research findings.

Outcomes/Conclusion: In 2009, the NINDS distributed \$111 million for PD research, including support for 14 Udall Centers of Excellence, the Neuroprotection Exploratory Trials for PD (NET-PD) clinical trials network, and the PD Data and Organizing Center (PD-DOC). The NINDS responds to more than a thousand PD inquiries every year and its PD information on the web receives more than 50,000 page views per month.

LWP5.04

From Car Park to Commissioning

Huston, C; Looker, J

NUH Trust, United Kingdom

Background: There is a lack of services specifically designed for individuals under 65 years of age when diagnosed with Parkinson's disease (PD) and a reluctance to be with older adults with PD. There was no younger persons service in Nottingham and a lack of appreciation by healthcare professionals of any service gap.

Aims and Objectives: The project was initiated by five young people with PD who wanted to do something positive to help themselves manage their PD with individuals of a similar age. The aim was to run a weekly exercise group which was specifically beneficial for individuals with PD and to provide a means of individuals who were under 65 at diagnosis with a forum to meet and talk with others in a similar position.

Methods: Five individuals supported by a physiotherapist and the Parkinson's UK, which funded a venue, provided equipment and spread the word by mouth that they were meeting one evening a week to exercise using a program based on the John Argue book 'Parkinson's Disease and the art of moving'. Initially this was simply an hours exercise with time to talk afterwards. It became apparent that individuals were improving rather than just maintaining their condition the physiotherapist asked to perform some berg balance Tests and a Lindop Scale. These were then repeated after three months and each subsequent three months to monitor progress. When it became apparent that scores were improving and that improvement was being maintained it was suggested that the group work towards commissioning the group with the local Primary Care Trust (PCT) to give it a more permanent financial basis and to make it more widely available.

Results: The PCT fund a weekly afternoon and an evening group for 40 people with PD. Berg and Lindop scores improve on average of 25% over the first three months and are then maintained by regular attendance. Bigger improvements are seen in the less able individuals. All individuals able to rise from the floor within three months of regular attending.

Discussion: Five individuals with PD decided they wanted a different service. By working together with the local Parkinson's UK branch, voluntary and health sector they have commissioned a service which they want to use and which has enabled them to maintain their health.

Conclusions: Individuals with PD can design and commission services. Targeted exercise can be effective in improving symptoms. Formal research project needs to be conducted to determine effectiveness of the exercises used.



General Topics

LWP5.05

Learning from Online Discussions about Parkinson's Disease Amongst People with Parkinson's and their Carers

Elleboudt, L¹; Verhaeghe, A²

¹UCB Pharma S.A., Belgium; ²InSites Consulting, Belgium

Background: The recent, rapid rise of online blogs, forums, review sites, social networks and other Web 2.0 applications has given the Parkinson's community a new and easily accessible platform to connect and share experiences with each other.

Objective: To collect, analyse and learn from spontaneous online discussions in the public domain related to living with Parkinson's disease (PD).

Methods: UCB Pharma SA in collaboration with InSites Consulting conducted a social media study of issues raised in online discussions about PD. The internet was monitored for user-generated-content on PD. Posts were analysed using text analytics. Over a period of 12 months (January 2009 - December 2009) over 11,000 publicly available and spontaneous online contributions about PD were collated, the majority from people with PD and their caregivers.

Results: Almost half of the online contributions included discussion of symptoms, of which most related to motor disturbances, followed by neuropsychiatric disturbances and sleep problems. Tremor and sleep disturbance were the two most commonly mentioned individual symptoms. Co-occurrence analysis revealed that tremor and sleep were most frequently cited together and pain was most frequently mentioned in combination with motor symptoms.

Online contributions from people with PD focused on motor symptoms and pain, whereas those from caregivers focused more on cognitive problems. Discussions highlighted that healthcare professionals focus mainly on motor symptoms, and that people with PD find it difficult to communicate with treating physicians about non-motor symptoms.

Conclusions: Online contributions by people with PD and their carers can offer valuable insights into living with PD. These direct insights help to highlight the unmet educational needs and the potential for new support programs to help the Parkinson's community in the future, particularly in relation to non-motor symptoms, such as sleep, cognitive problems and pain.

LWP5.06

A Qualitative Assessment of the Educational and Support Needs of People Living with Parkinson's Disease

Lindvall, S¹; Graham, L¹; O'Brien, E²; Davis, U²

¹United Kingdom; ²UCB Pharma SA, Belgium

Background: In 2009 the European Parkinson's Disease Association (EPDA) and UCB hosted Parkinson's disease (PD) discussion meetings with 17 people living with PD from the UK, Ireland, Belgium, Sweden, Switzerland, Slovenia and Spain.

Aim: To gain qualitative insights into the physical and emotional impact of PD, the perceived public understanding of the condition, and the unmet needs for support.

Methods: Ten people living with PD and seven family members participated. Telephone calls were hosted with each participant prior to the discussion meetings. Participants also had the option to conduct voluntary pre-work. The four-hour discussion meetings were lead by facilitators around pre-defined themes.

Results: PD was described as a 24/7 experience with emotions spanning denial, embarrassment and pride. For people with PD, the physical and emotional symptoms were intertwined, fluctuating and unpredictable. Varying needs for support information at different stages of the journey were expressed - from a basic outline with a positive tone at diagnosis to more comprehensive information when starting treatment and managing long term health. Participants had sought interactive partnerships with healthcare professionals, and family members expressed the benefits of their own engagement in the consultation. Advocacy groups were valued as a support and a forum for exchanging coping strategies and recognising the heterogeneity of the condition. A need was expressed and more face-to-face forums that could support the financial, physical and emotional impact of living with PD and for continued education among the general public, especially those providing services.

Conclusions: The discussion meetings identified a need for vehicles that would help to tailor information to the different stages of the disease, as well as tools that could help facilitate more interactive partnerships with healthcare professionals. The development of such initiatives could make a meaningful difference to the lives of people with PD.



General Topics

LWP5.07

The Birth of Parkinson's Society of India (PSI)

Nandita Deo (on behalf of Divakar Deo)

India

"Thirty seven years back when Parkinson's disease (PD) afflicted me, I had a choice to make. I could lead my life secluded from society and overtaken completely by the disorder PD brings or I could choose to come to terms with reality and make the most of what life had to offer and add meaning to it. I choose the later."
Divakar Deo.

Divakar Deo, born in Kerala, India, in 1946, developed Parkinson's disease at the age of 27 years whilst he was leading a very active professional and social life and lived with the disease for 37 years. It was a struggle to come to terms with the disease, and the restrictions it imposed on his life but the manner in which he dealt with it served as an inspiration to many.

The social awareness about the disease in India was limited and this inspired him to establish an organisation to increase social awareness and empower Parkinson's patients with the knowledge about the disease and to take charge of their lives. He founded the Parkinson's Society of India (PSI) in 1984 with encouragement from his neurologists and it was the first of its kind for Parkinson's patients in India. He organized 25 annual Conferences and free medical camps from 1985 to 2010. It was chaired by eminent neurologists from all over India, who delivered lectures and free consultations at the seminar. The media rendered its full support in spreading awareness about the disease.

The annual seminars empowered patients with knowledge about the pathophysiology of the disease, newer treatment options and free consultation with the neurologists. Physiotherapists demonstrated the need to keep physically fit. The role of Yoga and meditation for physical and mental well being was discussed. Psychologists also emphasized on the role of the carer and enthused patients to live life with a positive attitude and accept life's challenges.

The membership of the PSI grew over the years and currently has over 1000 registered members. The success of the society was an inspiration to start a Parkinson's disease and Movement Disorder Society in Mumbai, of which he was the Vice President.

For his social work on Parkinson's disease, he has to his credit, awards from Care and Share (Chicago), Rotary International, Bharat Bhavan Award from Government of Kerala and a write up about him in the medical journal Lancet. He was a part of a documentary made on PD for social awareness, which won the "Best Short Film" in the Apsara Awards. He strove to make amendments in the Government Law for the greater well being of Parkinson's patients.

His wife, three daughters and the joint family in which he lived offered him immense support.

Divakar Deo expired on the 6th of June 2010 at the age of 64, having lived a life which was a motivating example for those with Parkinson's disease. It was his dream to be able to attend the Second World Parkinson Congress in Glasgow, Scotland. His wife, Anjali Deo who was his carer for 37 years, is attending the WPC 2010 on his behalf.



Authors' Index

A		F	
Aimers, N LWP3.15	Farley, BG * LWP3.18
Alves, PG LWP3.05	Farris, SM LWP3.10
Amar, K LWP1.09, LWP3.13	Ferreira, LS LWP3.05
Ashford, L LWP1.06		
Ashton, J LWP3.11		
Atkin, AL LWP3.15		
Atkins, S LWP1.09		
B		G	
Ball, JG * LWP3.09	Giroux, ML LWP3.10
Barbosa, AP LWP3.05	Gonzalez-Ramos, G * LWP3.01
Bernard, CR * LWP3.02	Graham, L LWP2.01, LWP5.06
Berri, S LWP1.15	Graziano, M * LWP3.14
Bischoff, T * LWP3.08	Griffith, G * LWP1.10
Brooks, L LWP1.06	Grimes, DA LWP3.12
Browne, K LWP2.01	Gupta, A LWP3.02
Burns, JE LWP1.08, LWP1.13, LWP4.01		
C		H	
Capitanio, F * LWP1.03, LWP1.08	Heine, M * LWP1.02
Christenson, S LWP3.18	Heisters, D LWP3.11
Citron, J LWP1.06	Herman, L LWP1.06
Cohen, E LWP3.01	Herman, LA LWP4.01
Cohen, P LWP4.01	Hernandez, AJ LWP3.17
Cook, DG * LWP1.04	Hill, F * LWP4.02
Costa, AR LWP3.05	Holme, CA LWP4.02
Côté, D * LWP3.12	Howard, A * LWP3.10
CPT Patient Advisory Group LWP2.03	Hunter, C LWP3.19
Cummings, R LWP1.06	Huseman, K LWP1.06
		Huston, C * LWP5.04
D		J	
Davis, U LWP5.06	Jedlinski, S LWP4.01
DeCamp, W LWP4.01		
Di Rocco, A LWP3.01		
Dixon, M * LWP1.12		
Dumitru, E LWP3.17		
E		K	
Elleboudt, L * LWP5.05	Kancilija Staničē, A * LWP3.03
Emr, M * LWP5.03	Kell, P LWP1.06
		Knowles, S LWP3.15
		Kuhn, RG * LWP1.07
		Kummer, W LWP3.05
L			
		Lachance, L * LWP1.01
		Layne, RB LWP3.02
		Lemen, A LWP3.01
		Lif Kimchi, O LWP3.04



Authors' Index

Lindvall, S * LWP2.01, LWP2.02, LWP5.06
 Looker, J LWP5.04
 Lynnall, A * LWP3.16

M

Marques, JM LWP3.05
 Martinez, C LWP1.08
 Martins, FC LWP3.05
 Matthews, H * LWP3.11
 McCormick, M * LWP1.11
 Moreira, HBT * LWP3.05
 Morgan, L * LWP3.19
 Muralidhar, G * LWP1.06

N

Nelson, M LWP3.18

O

O'Brien, E LWP5.06
 Owens, S * LWP3.13

P

Papageorgiou, K LWP1.15
 Papatriantafylou, Y LWP1.15
 Paranhos, T LWP3.05
 Pessach, L LWP3.04
 Planton, S LWP4.01

R

Raican, D * LWP3.07
 Reynolds, H LWP3.13
 Robledo, I * LWP1.14
 Rossi, R LWP3.01
 Rowat, KM LWP3.12
 Ryan, PV * LWP5.01

S

Sieber, B-A LWP5.03
 Skoog, K-G LWP2.02
 Snelgrove, B * LWP1.05
 Stamford, JA * LWP1.07, LWP2.03
 Stepan, K LWP3.18

Stephenson, C LWP4.01
 Struiksma, AJC LWP5.02
 Sutherland, DP * LWP1.16
 Sutherland, DT LWP1.16

T

Tamir, R LWP3.04
 Tano, NB LWP3.12
 Telford, JR LWP4.02
 Thompson, C * LWP1.09
 Todaro, V LWP3.19

U

Urquhart, M LWP3.18
 Utting, B LWP1.09

V

van der Kolk, TA * LWP5.02
 Verhaeghe, A LWP5.05
 Verissimo, MV LWP3.05
 Vierck, E LWP1.04

W

Watson, C * LWP3.15
 Wheeler, J LWP1.06
 Williams, DT * LWP3.06
 Willocks, P LWP1.06, LWP4.01
 Wittekind, P LWP1.06

Y

Young, H * LWP3.17

Z

Zacks, M LWP1.05
 Zikos, P * LWP1.15
 Zouroudis, D LWP1.15

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