

Timo Montonen

Who's Afraid of Parkinson's?



My First Ten Hilarious Years

Language is an enemy, whom we talk to our side. So is Parkinson's.

Who's Afraid of Parkinson's?

The Finnish Association of Non-fiction Writers has supported the writing of this book.

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*“I’ll tell you in this book, how I climbed a ladder,
rose higher and higher step by step, toward the all
sanctifying Parkinson’s crown.”*

2015

- Foreword
- Organizations, Projects, Websites
- Is There an Editor in this Book?

“Oiva *A club for early onset and people with Parkinson’s at working age. I was crucial important to the birth and rouse of Oiva, and vice versa, from 2010 to 2014.”*

1. Foreword

I am translating from Finnish to English and at the same time editing the English version of this book. I have a pile of texts, which I have published in newspapers, social media and books from the year 2006 to 2015. The titles of my earlier books containing Parkinson's stories would be in English *Author's Book* (2008/2010/2015), *Towards a Better Life* (2011) and *I have Parkinson's, and I'm Proud of it* (2014). Sounds very positive or what you think? The last title, of course, is ironic, as you immediately realized.

About my English I would make a notification. Despite the fact, that I have learned English at various schools and at the university fifteen years all together and watched English movies over fifty years, I have used both Google and Microsoft Translators when needed. I do not hesitate to make lingual mistakes. Errors confirm that this is my personal story. There is a saying, that an error is the beginning of wisdom (or similar idiom in English?). Once when I was tutoring the top leaders of a big energy company, I tried to convince them that an error is a message. It is a message that should be heard and interpreted and from that base turn to learning and developing. But I don't aim to errors, I don't have to. They come without efforts, but the main point here is to become understood. This is what a Malaysian **Samuel Ng**, whom I had met in Montreal, Canada, at the 3rd World Parkinson Congress October 2013, wrote me in Facebook,

when he suggested that I should write to him an English version of my first book about Parkinson's. So, thanks him that this book exists.

I do not always tell the writing or publishing date of a certain publication, because I've edited, as I said, the writings for this book and written a lot of new things, varying from minor details to wider summaries. Old posts, read and forgotten, have been the springboard for fresh ideas, the restoration of forgotten memories, loose details compassing to the integration so that the crumbs are structured an entity.

I'll tell you in this book, how I climbed a ladder, rose higher and higher step by step, toward the all sanctifying Parkinson's crown. I flew toward an illusion, preceded in carrying out voluntary work and of the disease as like marking the boxes in a school experiment, conquered kilometer square of invalidity and influencing one after the other.

I remember how soon after getting the diagnosis I joined the Parkinson's Association of Southern Finland (PASF). I remember how I inquired the similarities and differences of numerous local clubs which were part of nearly twenty areal associations which made up the national Finnish Parkinson's Association. I remember how I tried to understand the meaning of quite massive hierarchical organization, when there were only seven or eight thousand members in the areal associations. I remember how I travelled through a simulation of nearby future; how I saw in my mind a cavalcade of positions of trust and of responsibility in various levels. I decided that one day I would be the chairman of a local club, a member of the board of directors in the areal association and in the

national association, and, of course, a union representative.

The fact that my Parkinson activity would take me from Helsinki, Finland, to London, UK, and to Montreal, Canada, in order to attend international meetings, never came in my mind. Neither did the fact that I would become gainfully employed in the association of my own disease. But so it was, when I dared to trust my ideas and apply for funding for new innovative activities – and give my own money, when the pleasure and benefit were near enough each other, such as the Canadian journey, so that before the 3rd World Parkinson's Congress I went with my daughter to Niagara Falls and pop star **Justin Bieber's** hometown Stratford...

But be patience, I'll tell all in time.

“Soon I noticed, that the Editor created a feeling of fiction.”

2. Organizations, Projects, Websites

Here is a list of organizations I've been working with, projects I've been involved with, websites I've been writing to and some other concepts important in my Parkinson scene:

- **1HOURMORE** A project of EPDA together with Italian Publisher, writer and medical company. 2015. Lizi Graham, Director of Fundraising and Global Communications, asked me to attend.
- **444 Parkinson's Traveler** A project of Marcus Cranston. I answered to Marcus in Facebook and took responsibility in Finland. Spring 2014.
- **APC** Advocates for Parkinson Committee. I offered to become an Ambassador of WPC2016, next day I was asked to join the APC. Spring 2014-to Autumn 2016.
- **dg** Diagnosis
- **EPDA** European Parkinson's Disease Association. Important international context to me especially 2011-2013, but later too.
- **FPA** Finnish Parkinson's Association. I've done co-operation since 2007.
- **Oiva** A club for early onset and people with Parkinson's at working age. I was crucial important to the birth and rouse of Oiva, and vice versa, from 2010 to 2014.

- **Palmenia Writing Program** My job for fifteen years at the University of Helsinki , 2000-2015.
- **Parkinson's at Work site** A web site created in the PW from the base of my ideas. 2012.
- **Parkinson Place/Stop** A social media, where I met angry opponents 2010-2014.
- **PASF** Parkinson's Association of Southern Finland, the areal association I belong to, joined 2005.
- **Parkinson's at Work project** Two years project I planned and made true with Anna-Maria Salonen, a part-time project worker, 2012-2013
- **PD** Parkinson's disease
- **pwp** person with Parkinson's, people with Parkinson's.
- **Seminar on Parkinson's Disease and Working Life** An important public whole day event of the PW. Spring 2013.
- **Summer Wind** The Special Training Center of Finnish Parkinson's Association.
- **WPC** Word Parkinson Coalition/Congress.
- **WPC2013** 3rd World Parkinson Congress, Montreal, Canada, 2013.
- **WPC2016** 4th World Parkinson Congress, Portland, Oregon, USA2016.



Parkinson's disease has not knocked down Timo Montonen, who was diagnosed at the age of 48. He tells his hilarious story through ten years of horror, joy, misery, hope, efforts and love.

After 10 years as a person with Parkinson's his condition is much better he ever could imagine in those early years of this severe, progressing disease, which is still waiting the cure.

As an Advocate for Parkinson Committee and an Official Blogger Partner of the 4th World Parkinson Congress Timo informs the Finnish Parkinson community of next Congress and gathers a delegation to travel to Portland (Oregon, USA, 2016, Sept. 20-23).

Timo Montonen is a Finnish author. He writes both fiction and nonfiction.



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