



Monday 30th November 2020

On-line Workshop

Free of charge - Direct link available for registered attendees only

WFIPP WORKSHOP – The Netherlands

/ Europe 2020 /

INCONTINENCE: how to shorten the patient journey

Therapies & Challenges: Learning from dialogue patient-doctor

LIST OF SPEAKERS:



Tine van den Bos is physiotherapist and president of Bekkenbodem4All since 2019. She was former president (2012-2017) of the Dutch Association for Pelvic Therapy (NVFB). Until September 2020 she was partly working for Leiden University, department urology. Nowadays she is still working as pelvic physio in paramedic Centre AdFysio in De Lier (near Delft). She is participant in advisory boards of patient organisations Lichen Sclerosis and Lichen Planus in the Netherlands. Recently she was appointed an honorary member of the NVFB.

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Mary Lynne Van Poelgeest-Pomfret is long-standing international patients advocate promoting the rights of patients at both national and international levels. A member of several patient advocacy movements and organizations like IAPO (International Alliance of Patient Organizations) and EPF (European Patients Forum). She has organized several workshops and given numerous presentations at major international scientific and patient advocacy organizations. She is also a member of the EFPIA Patient Think-tank. She became Vice-Chair of EFGCP as of March 2017 and is keen to actively contribute to the work of EFGCP, primarily from the patient perspective. She participated in the first EUPATI workshop of patient advocate experts in Frankfurt in September 2012 and actively participates in EUPATI. Lynne became the President of WFIP - World Federation for Incontinent Patients in January 2011: an international umbrella organization dedicated to enhancing the rights of patients suffering from incontinence and pelvic floor dysfunction in general. In this capacity the latest initiatives include a collaborative agreement with the European Association of Urology relating to patient advocacy issues. Also until April 2016, chairperson of the ICP – Netherlands Interstitial Cystitis Patients' Organization. More recently she became a member of the 'Core Board' for one of the EIP – AHA Focus groups led by the University of Valencia, Spain. Member of the PACT Steering Committee and also a member of the IMI project PARADIGM as patient engagement representative of EFGCP. Also as EFGCP a member of the Consortium for the new IMI project 'Conception'. Member of several scientific advisory committees and panels, including the EMA. Recently selected to become a member of the IMI panel of patient experts with active participation in, for example, healthcare decision-making. Within the EU.

Lynne worked for Shell in the Netherlands for 23 years and has a BA degree from the UK and Drs. Degree from Leiden University in the Netherlands.

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Dr. Michael van Balken studied medicine at the University of Nijmegen and was trained as a urologist in Deventer, Nijmegen and Verona. In 2003 he started in Rijnstate as a staff member within the urology partnership Arnhem-Velp-Zevenaar, in which he also fulfilled several organizational positions. Four years later, he obtained his PhD at the University of Amsterdam with a thesis entitled 'Percutaneous tibial nerve stimulation in lower urinary tract disorders'. Since 2014, Michael is an official trainer for new urologists within the Nijmegen cluster.

Michael van Balken is the (co-) author of more than 20 scientific publications, 5 books and almost 50 abstracts. In 2014, he has been declared TOP Urologist 2013 and was nominated for the title of TOP Doctor 2014. His special areas of focus are Functional urology (mostly incontinence problems), Reconstructive urology (including urethra reconstructions), Open surgery (bladder removal, complication surgery). He also specialises in the use of Social Media in healthcare and healthcare education, especially for low-literate people



After finishing his urologic residency in December 2019, **Martijn Smits** has become a staff member at the urology department of the Maastricht University Medical Centre (MUMC+, the Netherlands). In his clinical work he mainly focusses on functional urology (both male and female), neuro-urology and treatment of lower urinary tract dysfunction (LUTD) with neuromodulation. Already before starting his residency, he was involved in clinical research on evaluating sacral neuromodulation treatment, also at the same urology department. During his residency Martijn has gained a special interest in the organization of healthcare and is devoted to improve the healthcare consumers experience. In a five-year collaboration with Medtronic, Martijn goals to improve the care pathways for patients with LUTD in the MUMC+. This to achieve optimal patient experience and availability of care. In his presentation during this webinar, Martijn will provide insights into sacral neuromodulation therapy, into the recent innovations in this therapy and into the project mentioned above.

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Tonneke Vermeer had a career as a physiotherapist, and nowadays works as an author of historical memorial books. Since her youth she had to deal with constipation after she turned 40 developing into bowel and bladder incontinence and it took her many years to find a satisfying solution. In order to help other patients, she decided that she no longer wanted to hide her daily inconveniences. Her testimonial has already empowered several other patients.

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June Rogers is a Nurse Specialist, working at Bladder and Bowel UK under the umbrella charity Disabled Living. She has over 30 years' experience working with individuals with a wide range of bladder and bowel problems.

June has published widely and presented papers both nationally and internationally as well as winning many Awards for her work including an MBE in 1998. She has been involved with both the Department of Health and NICE regarding continence issues and is currently a member of the NHS England 'Excellence in Continence Care National Programme Board'.

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Dr Chris Chatterton began his career as a lab based scientist, with a specialist interest in biology and medical genetics. He has worked for UCL and Imperial College in London. During this period, Chris became interested in bioethics and medical sociology and decided to change fields, completing a PhD at Cardiff in this area in 2014. He is especially interested in health related stigma, particularly around obesity, mental health and continence issues.

He works as a freelance academic and science editor, and has worked for a number of universities and health related charities. As someone with continence problems himself, Chris has a deep understanding of the issues faced by individuals dealing with these difficulties. But Chris is passionate about bringing these issues out into the open, through public speaking, academic work, and health activism. Chris enjoys life beyond the health arena and work, with family and a passion for historic aviation taking up the rest of his time.

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Bert Messelink is a urologist and sexologist, working at the Medical Centre Leeuwarden. He has been working in the area of pelvic floor problems since 1995. He was involved in setting up the pelvic floor health care in the Netherlands. He set up pelvic care centres in different hospitals and always worked in multidisciplinary teams. He was chair of the first terminology committee about pelvic floor dysfunction. He educated many physiotherapists, sexologists and medical specialists in pelvic floor medicine. He is the founder of the Dutch pelvic floor patients organisation.

From 2000 on he dedicated his time to chronic pelvic pain. He is vice-chairman of the EAU guideline on chronic pelvic pain. He was chair of the IASP special interest group on pelvic pain. He organised the 1st international congress on Abdominal and Pelvic Pain in 2013. He contributed to 6 books on pelvic floor problems and pain. He chaired the committee who wrote the Dutch guideline on chronic pelvic pain this year. At this moment he is working on a new approach of care for patients with pelvic pain with the goal of shortening their patient journey dealing with this pain.

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UK based author **Luce Brett** became incontinent after the birth of her first child, and became in her words, a perennial patient on an odyssey through the corridors of shame. Increasingly perturbed by the shame and stigma surrounding incontinence, the embarrassment of treatment, what it is like to be a patient in the world of urodynamics, fanny physio, and the mesh, and the wider and more heart-breaking ramifications of a condition treated with such unkindness and lack of profile (beyond rude jokes and taboo) on a global scale. From a lack of funding for research or donations to charities for patients, to millions of people, predominantly women, not getting the health or cure they deserve, via the millions of £, \$ and € incontinence costs global economies, she made it her mission to write a book that would instigate debate and shine a spotlight on incontinence, the personal journey for patients, in all its harrowing, hilarious, messy, boring, depressing, and disconcerting detail. Her first book PMSL - Or How I Literally Pissed Myself Laughing and Survived The Last Taboo to Tell the Tale is published by Bloomsbury on 25 June 2020. It also be published in US, Australia and India.

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Fetske Hogen Esch is general manager and owner of Pelvic Physiotherapy Hogen Esch and F-act Pelvic Pain Clinic (www.pelvicpain.nl). She is committed to improving the care and treatment of pelvic floor problems and was the first Dutch pelvic physiotherapist to specialize in chronic pain in the lower abdomen and pelvic floor. Fetske is also one of the founders of the content of pelvic physiotherapy education in the Netherlands. Fetske Hogen Esch followed the Master Pelvic Physiotherapy and various courses and refresher courses at home and abroad. Fetske regularly speaks at (international) conferences and consults with medical specialists at home and abroad. She is also a teacher at Profundum Academy and a guest teacher at the National Training Center for Ultrasound (NTE).

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Myra Robson, Clinical Lead Physiotherapist (Lewisham & Greenwich NHS Trust) and "pelvicroar" co-founder'

I qualified from the University of East London in 1991 and became interested in the field of pelvic health a few years later. Once I had my two children that interest developed further and I now lead a pelvic health team at Lewisham and Greenwich NHS Trust in South London. I am particularly interested in the use of pessaries for prolapse management, mesh complications, pelvic floor exercise adherence and ways to address the stigma surrounding pelvic health conditions such as incontinence. I have worked closely with the team at Living With (formerly Propagator) and in 2013 we launched Squeezy, the physiotherapy pelvic floor muscle exercise App. This has become the number one paid medical app in the UK and has won several industry awards. It has been translated into Arabic, is selling worldwide and is also available for men and for people with Cystic Fibrosis. Living With have also developed a connected version of the app (SqueezyCX), which links to a clinician-led platform to support adherence and remote monitoring. In 2018, I co-founded the campaign group "pelvicroar" with specialist pelvic health physiotherapists Elaine Miller and Emma Brockwell. This is a collaborative campaign group to which everyone is welcome. We work through social media and our website, and have recently been shortlisted for a national award.

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Since 2008, **Marijke Darlang** has been working as communication manager for two hospitals in the Amsterdam area (Kennemer Gasthuis, Spaarne Gasthuis). Before 2008, she worked as a text writer and journalist for several theater companies and cultural organizations.



Philip Mulié is co-owner of Live Impact Event marketing, an agency that makes events more fun and engaging. Live Impact is well experienced in developing and executing event concepts for the healthcare industry. For example, Live Impact is an event partner for the Spaarne Gasthuis, Jeroen Bosch, Bravis and the MUMC+ hospitals. Philip has worked for multiple event agencies in the past. Here he has organized a wide variety of events for (inter-)national companies and non-profit organizations such as KPN, Heineken, SAP, NOC*NSF and the Ministry of Sport (VWS).

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Monica de Heide is a patient, and committed to Bekkenbodem4All as project coordinator. She is also owner of Convenir, a company that facilitates covenants between public, social and private parties in the field of the environment and food. She studied political science in Rotterdam and Paris.

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Thanks to all the speakers, organizers, sponsors and participants for making it happen!

