

WORLD ENDOMETRIOSIS ORGANISATIONS (WEO)

STEERING COMMITTEE



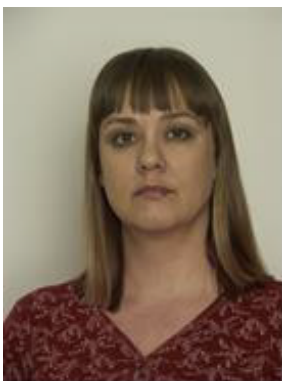
DEBORAH BUSH MNZM, QSM, Dip Tchg. LSB

Co-founder and Chief Executive; Endometriosis New Zealand
 Founder and Director EPP Coaching and Consulting (Endo and Pelvic Pain)
 World Endometriosis Society Board Trustee
 Principal; World Endometriosis Organisations

Deborah has had a global influence on the promotion and prevention of endometriosis worldwide. She developed the world's first Menstrual Health and Endometriosis **me™ programme** for schools in 1997 which has significantly influenced early recognition of symptoms and timely intervention in adolescents in New Zealand and has been endorsed by the World Endometriosis Society as the preferred education programme world-wide.

She has developed innovative health initiatives and programmes for schools, workplaces, hospitals and CME. She was instrumental in developing a Task Force team with the New Zealand Government and is implementing new Clinical Pathways for endometriosis. Her private practice EPP Coaching and Consulting integrates into four treatment centres in New Zealand offering multi-disciplinary expertise. Deborah presents frequently as key note speaker at international academic conferences and as MC at functions. Her many national and international awards reflect her achievements and contribution to the literature. Deborah was described as 'a pioneer, a visionary, a highly effective lay person in a specialised medical world' by the New Zealand Woman of the Year judges.

Deborah's achievements are reflected in the following awards: Queens Service Medal (QSM); Commonwealth Award for Excellence in Women's Health (Endometriosis NZ under her leadership); Paul Newman Award 2007; International Outstanding Service Award; Zonta International Woman of the Biennium 2011 – 2013; Woman of the Year – Health and Science, 2012; Woman of Influence Finalist 2014; New Zealand Order of Merit (MNZM) Queen Elizabeth Honours 2017.



ASDIS BRAGADOTTIR

I have been a board member of the Endometriosis Association of Iceland since 2015 and now manage the finances. I have a BBA degree from Acadia University, Wolfville, Nova Scotia, Canada. I work in a bank in Iceland and have been doing so for the past 30 years. Now I work in the back office at Kvika bank in Iceland as a specialist and manage settlements for securities among other things. I have two dogs, Irish setter, and they take up most of my free time

My endometriosis history is pretty long and for 31 years I went from one doctor to another, family doctors and gynecologists, but always got the same answer; there is nothing wrong, this pain is supposed to be like that and I'm sorry but there is nothing we can do for you. Finally I met a gynecologist who did listen to me, I had a MRI and six months later I had my first excision surgery that took six hours, and my life changed so much for the better.



ABEESHA TOUSSAINT B.A., M.A.

Abeesha is the founder and president of the Trinidad and Tobago Endometriosis Association [TTEA]. She, together with the TTEA Team, works with all stakeholders to improve health outcomes for endometriosis patients in Trinidad and Tobago. She has a breadth of knowledge, skills and experience from having worked in project management, communications, education, administration and in her roles as an active community member. She was awarded a master’s degree in Communication, Media and Public Relations from the University of Leicester, UK, in which her research focused on the newspapers’ coverage of women health issues namely endometriosis, infertility and dysmenorrhea in Trinidad and Tobago. Abeesha has a special interest in endometriosis and health communication. She has a number of publications and is a member of the International Association of Business Communicators and the World Endometriosis Society. She is genuinely sympathetic, passionate and dedicated to the cause.



ELSIE WANDERA-ODHIAMBO

Elsie is the Founder of the Endometriosis Foundation of Kenya launched in 2014. The organization seeks to unstereotype period pain & draw out the women who suffer in silence. She also advocates for women suffering with Endometriosis to break the silence & shaming of period pain in Kenya. The organization was born from her pain that as it took 8 years to diagnosis Endometriosis & Adenomyosis and has since undergone 3 surgeries to manage the presentation of the condition. The Foundation was launched as a platform for women to come together and have real conversations about the debilitating disease, medical interventions & natural options for easing the effects of the symptoms. EFK engages in conversations to raise awareness about Endometriosis through social media as a build-up to World Endometriosis Day/Awareness month in March every year.



MICHELLE E. MARVEL Endometriosis Research Center Founder & Executive Director.

Michelle E. Marvel is an accomplished business professional with vast experience across several fields, yet her passion is being an advocate for endometriosis, a disease that she has personally suffered with since her teens. Michelle’s “outside the box” vision led to the founding of the Endometriosis Research Center & Women’s Hospital (ERC) in early 1997. What was a conceptual idea to establish a research center at a prominent medical institute/facility transformed and developed into an organization that provided a voice for all those impacted by this puzzling disease. Today, more than two decades after its founding, the ERC continues to provide that voice and address the ever-growing need for endometriosis research, education, awareness and advocacy, patient engagement and support. For her daughter and the next generation, Michelle is dedicated to continuing the ERC’s mission to improve the quality of life for all those suffering with endometriosis in memory and honor of all those that have tragically taken their own lives.



EMMA COX

Emma joined Endometriosis UK as Chief Executive in February 2016. Along with Endometriosis UK's network of volunteers, Board of Trustees and small staff team, Emma works to ensure those with endometriosis and their needs are at the heart of all the charity does. As well as supporting those with endometriosis and raising awareness, the charity campaigns for change, such as to decrease diagnosis times, to improve treatments and so all can access the best care, and for more money to be invested in endometriosis research.

Through our Menstrual Wellbeing campaigning, Endometriosis UK has partnered with the Royal College of GPs to develop an online toolkit and e-learning modules for doctors on endometriosis and other menstrual wellbeing conditions, aiming to improve diagnosis. We have successfully campaigned to get Menstrual Wellbeing included in the new School Curriculum in England starting in 2020 - to overcome the taboo and embarrassment of talking about periods, and so in the future no-one has suffer as they are told what they experiencing is 'normal' and to just put up with it. Our schools campaign, informed by Deborah Bush and the New Zealand me™ programme for schools, is a great example of how Endometriosis Associations from different countries can learn from and support each other to spread good ideas and best practice. Emma's background is as strategic change management specialist with over 25 years' experience gained working in volunteering, membership organisations including Diabetes UK, NUS and the Chartered Quality Institute. Emma has an MSc in Organisational Behaviour and an MBA.



FEMKE JANSEN was diagnosed with endometriosis in 2010, after a long period of increasing symptoms and many hospital visits. Before founding and becoming the chair of the Belgian Endometriosis Association (EndoHome) in 2015, she worked as a volunteer and later as a researcher for the Dutch Endometriosis Association. Their research work has been rewarded on several international conferences. EndoHome focuses among other things on organising support groups and creating awareness on many levels. EndoHome's national information-day has become a yearly sold out event. Femke has several (inter)national publications and is currently involved in the development of new ESHRE guidelines. She has a PhD in biomedical science. Nowadays, she works in a hospital as a medical

scientist. Femke is passionate about awareness, advocacy and research. Her three daughters motivate her to make a difference in the endo-world.