

We Can Work It Out* The consensus on current management of endometriosis

“Try to see it my way
Only time will tell if I am right or I am wrong
While you see it your way
There’s a chance that we may fall apart before too long
We can work it out

Think of what you’re saying
You can get it wrong and still you think that it’s alright
Think of what I’m saying
We can work it out and get it straight, or say good night
We can work it out
We can work it out”

The Consensus on Current Management of Endometriosis is published in the prestigious journal *Human Reproduction* (1). And it is **free access** for all of you. So, the World Endometriosis Society got it straight.

I am not sure there is another gynaecological disorder with so many grey areas in so many aspects, including pathogenesis, diagnosis, and therapy, and with so many treatment alternatives for so many diverse clinical situations. If this is true, it should come as no surprise if “experts in the field” disagree so much and argue on

Inside this eJournal

- 1 President’s message
- 3 Upcoming meetings
- 4 A word from the editor
- 4 News: Paolo Vercellini presented with Rokitansky Prize
- 5 The 4th Nordic Congress on endometriosis
- 7 News: Rodolphe Maheux Travel Grants
- 8 Submit your abstracts now to WCE2014!



A/Professor Paolo Vercellini
WES President

every possible occasion, from debates at meetings to diverging opinions expressed in scientific journals.

The final victim of this disorientating scenario is the woman with endometriosis. Depending on the referral hospital or caring physician, she will get very different diagnostic modalities, and undergo surgery, or medical therapy, or IVF, or simple observation for the same problem. Too often the medical decision is not taken based on the available evidence, but on what the individual gynaecologist is able to offer. Moreover, conflicts of interest may play a role, especially in countries without a robust national healthcare system.

The Cochrane Collaboration began its activity already twenty years ago, and several systematic reviews and meta-analyses have been published on endometriosis by the Cochrane Menstrual Disorders and Subfertility Group (CMDSG). We are in debt to these respected colleagues, who voluntarily identify, select, analyse, and pool the best published data in order to define the most beneficial available treatments for our patients. However, randomised controlled trials are not available in several areas of the endometriotic disease, which thus escape the watchful scrutiny of the CMDSG. Moreover, the CMDSG has not yet addressed the issue of diagnostic modalities and tests. Therefore, there is already ample room for personal views and subjective medical approaches, although this does not appear to constitute an advantage for women with endometriosis.

This is why 56 people from 34 organisations from all continents came together in Montpellier after the 11th World Congress on Endometriosis, with the objective of addressing all the major issues in endometriosis, analysing the evidence, discussing discrepancies, confronting with each other, and eventually reaching a consensus, which is, in synthesis, a general agreement resulting from the balance of divergent views.

This was not a cheerful reunion of a merry band of old fellows, but a workshop following strict norms and criteria, which are well explained in the original article (1). In other words, the entire process was based on precise, predetermined, and validated scientific rules.

I am not writing to emphasise self-referentially how good we have been in putting together another guideline on management of endometriosis, as there are already several other respected available recommendations, including those of ESHRE, ASRM, RCOG, and SOGC (2-6). Moreover, I have personally contributed very little to the final document, which is the result of the strenuous efforts of Neil Johnson and Lone Hummelshoj, who worked really hard for so many months. We must all be grateful for their motivation and exceptional capabilities in organising the meeting, defining the methods, putting together the innumerable pieces of evidence, and drafting the manuscript.

In my view, what makes this document different from the existing ones is the choral participation of so many organisations including, for the first time, representatives of patients. Therefore, the Montpellier Consensus paper does not express the position of a single society, which may be more prone to favour a specific approach (eg. surgery, drugs, or ART), and thus is more likely to result in a balanced “compromise” between dissimilar views. In fact, we know that, even when the evidence is systematically searched, the results of data pooling may differ based, as an example, on the institution or company, which commissioned and supported the investigation.

I am particularly satisfied with the collaboration of patients’ organisations. It was time to hear the voices of women with endometriosis. They know much better than we do what really matters to them. The time has come to select therapeutic alternatives based on their preference, not on what we think is better for them. Only individual patients are able to balance the level of risk they are willing to accept for achieving relief from the symptom that is the most distressing for them. Any

single woman knows what is more important in her life and different people may choose differently or may have different opinions from their doctors. Patient-centred medicine is here to stay (7), and all major medical journals are discussing the advent of the “patient revolution” (8). Now, more than ever, our moral obligation is informing fully and transparently and accompanying the women with endometriosis empathically through the shared-decision making process, leaving behind the old paternalistic approach (9).

But putting the patient at the centre of our professional activity is not limited to clinical care, and extends also to the research field. In this regard, patients should be involved also in planning future investigations in order to identify the objectives that are more important for them (10). In other words, women with endometriosis may guide the efforts of researchers in focusing on the outcomes that can impact most on their health-related quality of life. In this regard, the organisers of the next workshop on the definition of future directions for endometriosis research (11) are advised.

Certainly there will be criticisms and disagreements on both the methods and the results of the consensus process and, indeed, on several issues where a consensus could not be achieved. Discussion is expected and even fostered, as debate is a key factor in scientific advancement, and we need to know the opinions of as many colleagues as possible, as well as the thoughts of women with endometriosis. We will take diverging views into high consideration, implementing modifications through subsequent revisions. Ameliorating the consensus document is among our objectives and we trust it is feasible...with a little help from our friends!

Paolo Vercellini
President
World Endometriosis Society



The WES Montpellier Consortium, Montpellier Medical School, 8 September 2011

References:

1. Johnson NP, Hummelshoj L for the WES Montpellier Consortium. Consensus on current management of endometriosis. *Hum Reprod* 2013;28:1552-1568
2. Kennedy S, Bergqvist A, Chapron C, D'Hooghe T, Dunselman G, Greb R, Hummelshoj L, Prentice A, Saridogan E. ESHRE Special Interest Group for Endometriosis and Endometrium Guideline Development Group. ESHRE guideline for the diagnosis and treatment of endometriosis. *Hum Reprod* 2005;20:2698-2704.
3. Practice Committee of the American Society for Reproductive Medicine. Endometriosis and infertility: a committee opinion. *Fertil Steril* 2012;98:591-598.
4. Practice Committee of the American Society for Reproductive Medicine. Treatment of pelvic pain associated with endometriosis. *Fertil Steril* 2008;90:S260-269.
5. Royal College of Obstetricians and Gynaecologists. The investigation and management of endometriosis. Green-top Guideline 2006;24:1-14.
6. Leyland N, Casper R, Laberge P, Singh SS, SOGC. Endometriosis: diagnosis and management. *J Obstet Gynaecol Can* 2010;32:S1-32
7. Godlee F. Partnering with patients. *BMJ* 2013; 346:f3153.
8. Richards T, Montori VM, Godlee F, Lapsley P, Paul D. Let the patient revolution begin. *BMJ* 2013;346:f2614.
9. Moynihan R. The future of medicine lies in truly shared decision making. *BMJ* 2013;346:f2789.
10. Krumholz HM, Selby JV, Patient-Centered Outcomes Research Institute. Seeing through the eyes of patients: the Patient-Centered Outcomes Research Institute Funding Announcements. *Ann Intern Med* 2012;157:446-7.
11. Rogers PA, D'Hooghe TM, Fazleabas A, Giudice LC, Montgomery GW, Petraglia F, Taylor RN. Defining future directions for endometriosis research: workshop report from the 2011 World Congress on Endometriosis in Montpellier, France. *Reprod Sci* 2013;20:483-99.

*Modified from Lennon J. and McCartney P. "We can work it out". The Beatles, Parlophone, UK, 1965

Upcoming meetings

ESHRE PCC: Impact of pelvic pain and uterine bleeding on quality of life	7 July 2013 London, United Kingdom
29th Annual Meeting of ESHRE	7 – 10 July 2013 London, United Kingdom
SGI Summit: Innovations in Obstetrics and Gynaecology	6 – 8 September 2013 Istanbul, Turkey
69th Annual Meeting of the ASRM held together with the IFFS	12 – 17 October 2013 Boston, USA
22nd Annual Meeting of the ESGE	16 – 19 October 2013 Berlin, Germany
42nd Annual Meeting of the AAGL	10 – 14 November 2013 Washington DC, USA

To view the full congress schedule go to <http://endometriosis.org/congress-schedule>

Counting Down!

The count down to WCE2014 in São Paulo will soon hit the 300 days mark. It is hard to believe that the next tri-annual meeting is less than a year away. The fantastic memories of Montpellier are still so fresh! I don't need to remind you that this conference is one for you and by you.

This is not only because the WES membership has for the first time been able to directly help put the programme together through a vote to prioritise topics of interest. The World Congress of Endometriosis has also always been a scientific meeting heavily biased towards presentations by the membership, rather than invited speakers. So, grab your chance to take the stage and submit your abstract! [The website is now open for online submissions!](#)

In this issue, our President Paolo Vercellini, pays tribute to the efforts of the Montpellier Consortium, spearheaded by Neil Johnson and Lone Hummelshoj. These significant efforts have now culminated in the WES Consensus published in Human Reproduction and freely available to all. Paolo quite rightfully points out that this is the first time that patient group representatives have been active participants in such a process. It is hoped that their experience living with this disease will continue to shape research and clinical management.



A/Professor Luk Rombauts
WES eJournal Editor

Another interest group that provided invaluable input in Montpellier were endometriosis nurses. In this eJournal we hear more about their special relationship with patients and their contribution to the holistic management of endometriosis. Vibeke Amelung brings a personal report on the 4th Nordic Congress on Endometriosis on [page 7](#).

Finally, Maurico Abrao, the WCE2014 convener, invites us all to submit our abstracts for the meeting in São Paulo less than a year away!

Paolo Vercellini presented with Rokitansky Prize

WES President, Paolo Vercellini, was honoured with the Carl von Rokitansky Prize 2013 at the recent 10th German Endometriosis Congress, held in Linz, Austria.

The Carl von Rokitansky Prize has been created by the SEF (Stiftung Endometrioseforschung) to honour those who have contributed extensively to the field of endometriosis, and Dr Vercellini was its first recipient.

In addition to the memorable sculpture, the prize includes €2,500, which Dr Vercellini has donated towards the Rodolphe Maheux Travel Fund to enable young researchers to attend the 12th World Congress on Endometriosis next year in São Paulo (see [page 7](#)).

Congratulations to Dr Vercellini!



The Rokitansky Prize, which is made from steel and perhaps symbolizes implants, cysts and revascularization, is created by Felix Buchsbaum from the City of Tragwein in Austria. The colour is brownish like hemosiderin.

The 4th Nordic Congress on endometriosis

Vibeke Amelung RN

Svendborg Hospital, Svendborg, Denmark
vibekeamelung@hotmail.com

The 4th Nordic Congress on Endometriosis was held in Turku, Finland from 23-25 May this year. This time there were over 200 participants from 15 countries. Quite an achievement for the Nordic. I am already looking forward to 2016, when NEC will be in Iceland.

I have had the opportunity to participate in 2 earlier congresses on endometriosis: the 3rd Nordic Endometriosis Congress in Trondheim, Norway in 2009, and the 11th World Endometriosis Congress in Montpellier, France, in 2011. They were both very interesting - but at this congress in Turku something happened to us nurses: for the first time we were mentioned as collaborators with the doctors in their treatment for the women with endometriosis and recognised as full members of a team. And for the first time nurses had contributed posters on their own at the congress.

The nurses' education today gives them a good background to work on their own with very little supervision from doctors. Some countries already have "clinical nurses", nurses who are specially trained to start up a treatment or treat patients without having been seen or examined by a doctor first. These nurses are valuable when treating patients with chronic diseases, because these are typically in need of a more holistic approach to cope with the disease.



Vibeke Amelung RN,
WES Board Member

Nurse collaboration across countries

Grete Christensen – Chairman of the Danish Nurses' Organisation [Dansk Sygeplejeråd, red.] – said in Melbourne last month: "The Nordic countries are facing identical challenges in their health services, because we are experiencing a rapid increase in chronic diseases. The lack of care has a negative influence on their health and quality of life". And she asked that SSN [Sygeplejerskenes Samarbejde i Norden = the Nordic Collaboration of Nurses, red.] should work together and have a goal of making clinical nurses the cornerstone in the healthcare systems in the Nordic countries. SSN represents more than 300,000 nurses from Finland, Norway, Sweden, Iceland, the Faroe Islands, and Denmark. If we can work like this, the patients will only meet few people during the treatment of their disease, and the doctors will be able to take care of the patients with severe disease, while being reassured that the other patients are also treated properly.

Centralisation of endometriosis treatment

At the end of the congress in Turku discussion turned to the topic of centralised endometriosis teams, working in the various clinics. In Svendborg, Denmark, we have such a team, but when we started in 2008, we weren't really aware of the need for an endometriosis clinic. First we started out with one day a month, and last year – 2012 – we had the clinic open every Thursday. If the woman has been seen once in the clinic, she doesn't need a new referral from a GP, but can just phone us and arrange for

an appointment at the clinic. And here the nurses have a great task, because it is us, who answer the phone and talk with the women. Many times the doctors never get around to talk with the women, because the nurses have solved the problem already, or s/he will have briefed the doctor before the appointment so that s/he knows exactly what the problem is. With these kind of patients, which will be in contact with the clinic over several years, it is essential they have someone they trust and know when they contact us. Our clinic has two doctors and three nurses, so we know almost every patient going through the clinic. In our clinic we also have a dietician, a psychologist and, hopefully this year, we will also get an acupuncturist. We have a good collaboration with the Danish Endometriosis Society, who are also willing to come and talk with our patients or if we have some presentation days.

Nordic countries leading the way?

In Turku there was also discussion about co-operation between the Nordic countries. I personally think it is a great idea because in Denmark we are maybe 8 – 10 nurses who work with and have an interest in endometriosis, so we really need someone else to talk to and share ideas with, etc. I also think the Nordic countries are sufficiently alike also in terms of their

educational models for nurses, that this will not be a problem. Maybe here will be an opportunity to get those nurses who are working with young people (primary schools, high school, etc.) to participate as well, because this is an area where we really need to get information out. Fortunately here in Svendborg we have a nurse who previously worked in our department (not with endometriosis) who has been employed at the high school, so she gets a lot of information and pamphlets from us to distribute.

I am really looking forward to the next couple of years, because there is so much we – both doctors and nurses – can do together for women with endometriosis, and as one of the speakers in Turku said: “we need to have some young ones to take over”. In my opinion, if we lead by example showing how to work together across borders and across professional educational levels, someone is bound to follow.

Finally, I invite you all to watch out for the first nurse pre-congress course on 30 April 2014 in connection with the 12th World Congress on Endometriosis – I hope to see many of you in São Paulo next year!



Contributions to the next issue of the eJournal should be sent to us by **20 August 2013**
ejournal-editor@endometriosis.org

Previous issues of the WES eJournal are **available from our website**

Rodolphe Maheux Travel Grants

The Rodolphe Maheux Travel Grant has been created in honour of the World Endometriosis Society's co-founder to carry on his mission of enabling young researchers to attend scientific meetings. Each grant includes registration for the main congress, as well as travel/accommodation expenses covered up to the amount of Euro 800.00.

Successful applicants must:

- be a fellow doing clinical/basic research in endometriosis
- be under the age of 40
- have a least one publication on endometriosis to their name
- have at least one accepted abstract for the World Congress they apply to attend
- be able to justify why s/he cannot raise funding from elsewhere to attend the World Congress

WES currently has four travel grants available, which have been made possible by donations from Paolo Vercellini, the Mangiagalli Journal Club Association, as well as Professor Mette Moen.

Email WES if you wish to contribute to further grants

Applications for the RM Travel Grant for WCE2014 opens on 4 July 2013 and closes on 7 October 2013.



Submit your abstracts now to WCE2014!

The World Endometriosis Congress presents an excellent opportunity for acquisition and distribution of knowledge in the field of endometriosis. As in previous congresses, we dedicate a significant portion to feature new studies from basic science research to clinical and surgical perspectives, in order to advance our understanding of the disease.

The 12th World Congress on Endometriosis will feature:

- 10 main clinical and scientific seminars addressing current conundrums in endometriosis (all abstract driven, providing an opportunity to everyone in the community to be heard)
- 7 keynote lectures
- 3 industry-sponsored lunch symposia
- 100+ oral abstracts distributed over the 10 main seminars and 9 free communication sessions (addressing both clinical and scientific issues)
- 3 video sessions

This WCE is the first one where we include a video session – with an award for the best video. Awards will also be presented to the best clinical presentation by a researcher under the age of 40, and the best scientific presentation by a researcher under the age of 40.



Professor Maurício Simões Abrão
WCE2014 President

Don't miss out on this opportunity to feature your work!
Submit your abstracts now

Deadline for abstract and video submission is
7 October 2013.

Mauricio Abrao
WCE2014 President

12TH WORLD
CONGRESS ON
ENDOMETRIOSIS
30 April to 3 May 2014 - São Paulo, Brazil

Adding pieces to the puzzle of endometriosis

World Endometriosis Society • Central Business Office • 89 Southgate Road
London • N1 3JS • England • t +44 (0)77 1006 5164
www.endometriosis.ca • wes@endometriosis.ca

ISSN 1993-3924