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l'Union européenne

The #ENDOS project is part of an ambitious and profoundly human initiative: providing patients with endometriosis with the tools they need to better understand their condition, accelerate diagnosis, and simplify interactions with the medical community. Through a comprehensive and inclusive approach, this project aims to transform the challenges of endometriosis into opportunities for learning, collaboration, and progress.

This training module is designed to explore the key themes that support this vision. You'll discover how to:



**STRENGTHENING
THE
THERAPEUTIC
ALLIANCE**

**RESPECT CHOICE IN
HEALTHCARE**

**SUPPORT
SCIENTIFIC
RESEARCH**



**RECOGNIZING THE
DISEASE AND ITS
MANIFESTATIONS**

**PROMOTING
HEALTH
DEMOCRACY**

**ENHANCE
PATIENT
PARTNERSHIPS**



TRAINING TO BECOME THE PROTAGONIST OF YOUR OWN HEALTH JOURNEY



In France, the principle of healthcare democracy enshrined in the 2002 Kouchner law (1) now implies patient participation in their own care. Healthcare users make informed choices and are fully involved in their own care throughout their lives.

The 3 dimensions necessary for the correct exercise of healthcare democracy:

**1. KNOWLEDGE OF THE DISEASE 2. CHOICES
IN THE TREATMENT PATH 3. THE
THERAPEUTIC ALLIANCE**



1 ENDOMETRIOSIS KNOWLEDGE: DISCERN MY BELIEFS

If you get pregnant, you will recover!



Women suffer from endometriosis because they are less likely to get pregnant!



Menstrual blood contaminates you and makes you sick!



Science needs time to build solid knowledge about endometriosis (2).
Current scientific research seeks to understand the mechanisms of the disease according to various hypotheses: immune, inflammatory, environmental and/or bacterial.

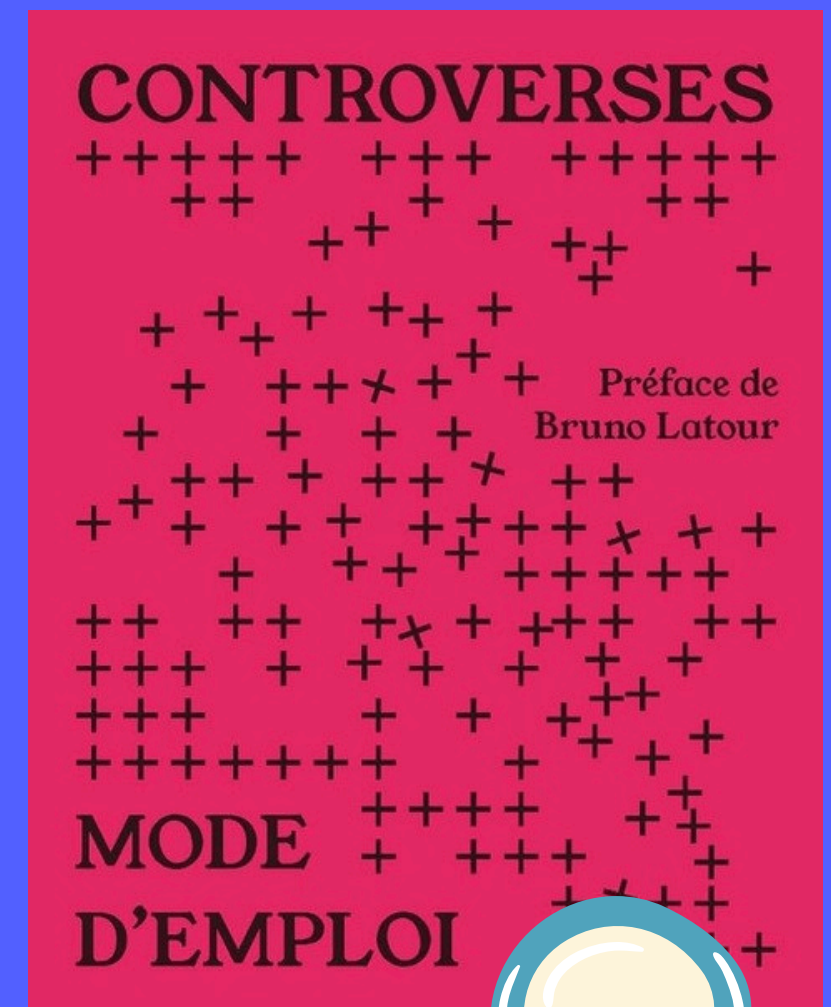


1 SCIENTIFIC CONTROVERSY: ENDOMETRIOSIS KNOWLEDGE

Today we are witnessing a fascinating phenomenon: science being formed right before our eyes. This volatile and fluid period is one in which scientists explore and attempt to agree on scientific truth, built on a foundation of solid evidence. The history of science teaches us that scientific discoveries are always the result of a long and challenging process, and numerous scientific controversies, before they can settle down, until the next dispute. (3)

The current controversy surrounding endometriosis is

This is such a compelling case study that it is being studied by students at Sciences Po Paris within the Centre for the Exploration of Contemporary Controversies, directed by sociologist Thomas Tari. (4)



SCIENCE STUDENTS PO PARIS

I INFORMATION ON ENDOMETRIOSIS WITH MARINA KVASKOFF



Marina Kvaskoff, epidemiologist and researcher at Inserm specializing in endometriosis research in France. Inserm awarded her the Science and Society-OPECST prize in 2023. (6)



What drove me to study the disease was injustice. The fact that it is not studied thoroughly, the fact that so much suffering has been ignored for so many years. There are people whose suffering is denied because they cannot see, because nothing emerges from the diagnostic images, and so on. For me, what it gave me is a very clear mission. An alignment between my commitment as a person and my missions as a researcher. And it is also a field in which we know very little. There is always something new to learn. (5)

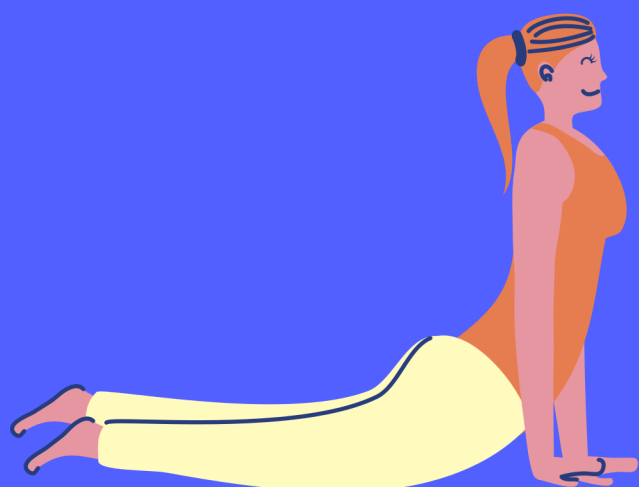
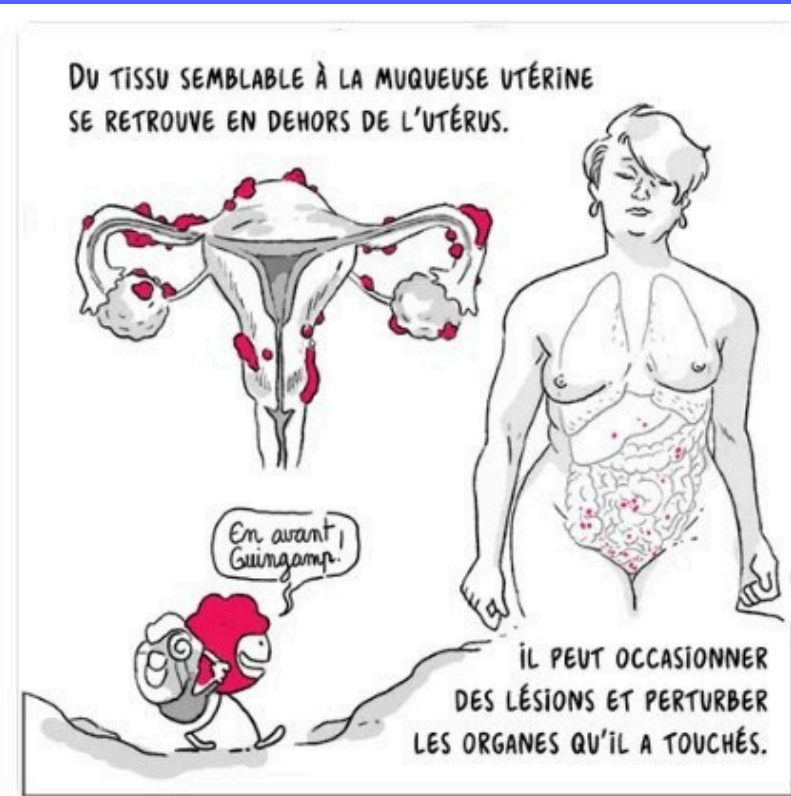
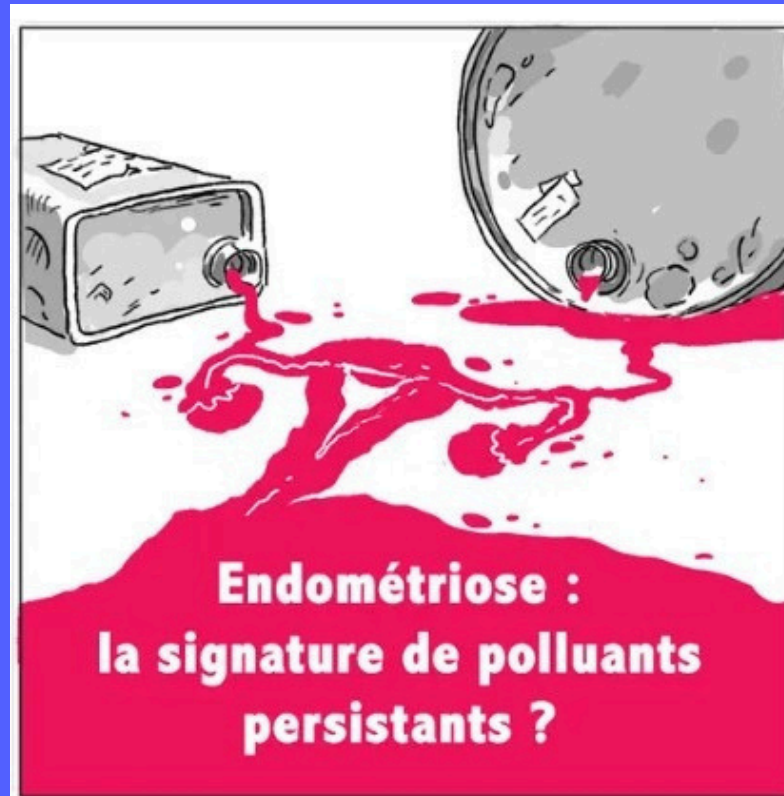
1 UNDERSTANDING ENDOMETRIOSIS WITH INSERM AND INRAE

Marina Kvaskoff calls for a broader mobilization of related scientific communities (particularly those involved in cancer research, developmental biology, epigenetics and neuroscience) to undertake research commensurate with the challenges. (7)

In France, Inserm and INRAE are joining forces to conduct joint research on understanding endometriosis and the environmental causes responsible for its development. (8)



1 UNDERSTANDING ENDOMETRIOSIS WITH INSERM AND INRAE



1 UNDERSTANDING ENDOMETRIOSIS WITH INSERM AND INRAE



LES CAUSES DE L'ENDOMÉTRIOSE RESTENT MAL CONNUES. ON SAIT CEPENDANT QU'ELLES SONT MULTIPLES : GÉNÉTIQUES, HORMONALES... ET ENVIRONNEMENTALES !

LE SYSTÈME REPRODUCTIF FÉMININ EST TRÈS SENSIBLE AUX PERTURBATEURS ENDOCRINIENS, COMME CERTAINS POLLUANTS ORGANIQUES PERSISTANTS QUI ALTÈRENT LA FONCTION DES HORMONES.

D'AILLEURS DES CHERCHEURS ONT TROUVÉ UN LIEN ENTRE UNE EXPOSITION À CERTAINS POLLUANTS ORGANIQUES PERSISTANTS (POPS) ET LA PROGRESSION DE L'ENDOMÉTRIOSE.

CES POPS SONT DES SUBSTANCES CHIMIQUES ISSUES DES ACTIVITÉS HUMAINES, COMME L'INDUSTRIE OU L'AGRICULTURE.

ILS S'ACCUMULENT DANS LA CHAÎNE ALIMENTAIRE, PUIS DANS L'ORGANISME.

LES CHERCHEURS SOUHAITENT CONFIRMER LE RÔLE DE CES POLLUANTS DANS LA MALADIE ET COMPRENDRE LES MÉCANISMES EN CAUSE.

JE VAIS TRAVAILLER AVEC L'UN D'ENTRE EUX, GERMAN CANO-SANCHO, DE L'INRAE DE NANTES.

NOUS ALLONS ANALYSER UN GROUPE DE 625 FEMMES RECRUTÉES DANS LES ANNÉES 90. PARMI ELLES 125 ONT DÉVELOPPÉ PAR LA SUITE UNE ENDOMÉTRIOSE.

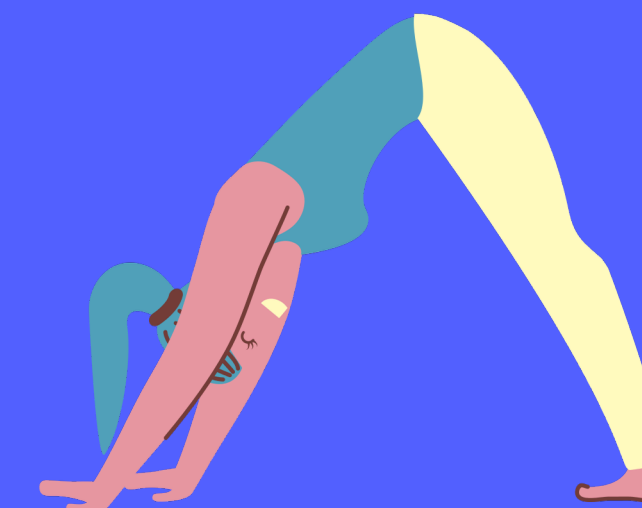
IL S'AGIRA D'UNE DES PLUS GRANDES ÉTUDES MENÉES À CE JOUR SUR LE SUJET.

POUR CHAQUE FEMME, NOUS DISPOSONS DE PRÉLÈVEMENTS SANGUINS RÉALISÉS À L'ÉPOQUE, QUAND L'EXPOSITION AUX POPS A ÉTÉ LA PLUS ÉLEVÉE, JUSTE AVANT LEUR INTERDICTION.

DEPUIS, CES FEMMES RÉPONDENT RÉGULIÈREMENT À DES QUESTIONNAIRES SUR LEUR MODE DE VIE, CE QUI NOUS PERMET DE SUIVRE LEUR ÉVOLUTION ET DE VOIR À QUOI ELLES ONT ÉTÉ EXPOSÉES.

DES MARQUEURS SANGUINS SONT GÉNÉRÉS PAR L'EXPOSITION AUX POLLUANTS. LES IDENTIFIER NOUS PERMETTRA DE CORRÉLER L'EXPOSITION AUX POPS AVEC L'ENDOMÉTRIOSE.

Composés perfluorés
Dioxines
DDT
TCDD
PFOA
Hexachlorobenzène
PCBs
PFOS
Pesticides organochlorés
HCB



1 UNDERSTANDING ENDOMETRIOSIS WITH INSERM AND INRAE

ET C'EST COMPLEXE, CAR IL Y A UN GRAND NOMBRE DE POLLUANTS, QUI PEUVENT S'ASSOCIER DANS LA NATURE ET FORMER DES COCKTAILS AUX EFFETS INCONNUS.

CHEZ LES FEMMES NON MALADES AUJOURD'HUI, ON PEUT TROUVER DES MÉLANGES COMBINANT ENTRE 50 ET 90 POLLUANTS DIFFÉRENTS, DONT CERTAINS INTERDITS DEPUIS 30 ANS.

TOUS CES COMPOSÉS SONT SEULEMENT DÉTECTABLES PAR DES TECHNIQUES INNOVANTES À HAUTE RÉOLUTION CAR ILS NE SE RETROUVENT QU'À TRÈS FAIBLES DOSES DANS LE CORPS.

OR, MÊME À TRÈS FAIBLE DOSE ILS PEUVENT AVOIR UN EFFET SUR LE CORPS.

EN PLUS DES MARQUEURS DES POLLUANTS, NOUS ALLONS CHERCHER DES MARQUEURS SANGUINS DE L'ENDOMÉTRIOSE.

ET NOUS COMPARERONS TOUS CES MARQUEURS, CHEZ LES FEMMES AVEC ET SANS ENDOMÉTRIOSE.

Marqueur PCBs sans endométriose

Marqueurs endométriose et marqueur hexachlorobenzène

Marqueurs endométriose



EN CORRÉLANT LES RÉSULTATS DES ANALYSES SANGUINES AVEC LES RÉPONSES DES QUESTIONNAIRES, NOUS POURRONS, GRÂCE À DES MÉTHODES STATISTIQUES AVANCÉES, LIER LE RISQUE D'ENDOMÉTRIOSE AVEC L'EXPOSITION AUX MÉLANGES DE POLLUANTS.

NOTRE PROJET A ÉTÉ SÉLECTIONNÉ DANS LE CADRE D'UN APPEL À PROJET DE LA FRM QUI FAVORISAIT L'INTERDISCIPLINARITÉ. C'EST LA MISE EN RELATION DE PLUSIEURS EXPERTISES QUI PERMET DE MIEUX ANALYSER ET ÉVALUER CETTE PROBLÉMATIQUE COMPLEXE.

Marina Kvaskoff
Experte épidémiologiste
INSERM / Villejuif

German Cano-Sancho
Expert étude des POPs
INRAE / Nantes

Fabien Jourdan
Expert Bio-informatique
INRAE / Toulouse

TOUT CELA NOUS PERMETTRA D'ÉCLAIRER LA PRÉVENTION ET DE FAIRE D'AVANTAGE PRENDRE EN COMPTE L'ÉVALUATION DES RISQUES CHIMIQUES DANS LES POLITIQUES DE SANTÉ PUBLIQUE.

1 KNOWLEDGE ABOUT ENDOMETRIOSIS: PARTICIPATORY RESEARCH

Scientific research in France is also progressing thanks to ComPaRe Endometriosis (10), a cohort of adult patients affected by endometriosis whose aim is to study:

- The natural history of endometriosis (the evolution of symptoms and disease characteristics over time); the factors that determine a favorable or unfavorable course of the disease; the factors that lead to a better response to treatment; the heterogeneity of endometriosis through an
- analysis of the characteristics associated with different forms of the
- disease, including adenomyosis; the circumstances of diagnosis and the patient's treatment pathway; and the impact of the disease on patients'
- daily lives.

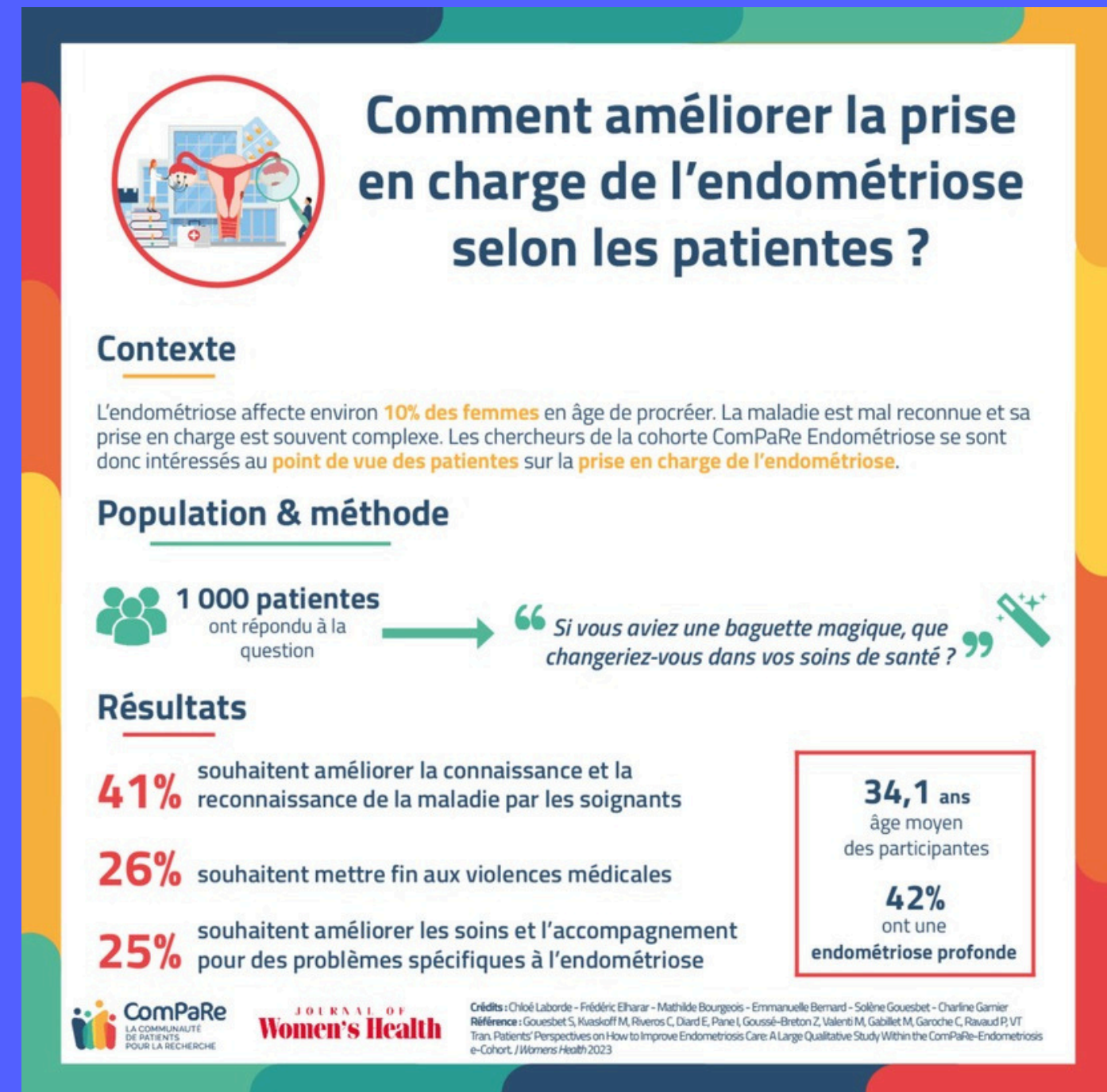


1 KNOWLEDGE OF ENDOMETRIOSIS AMONG HEALTHCARE PROFESSIONALS

In 2023, a scientific study surveyed 1,000 patients, asking them: "If you had a magic wand, what would you change about your healthcare?". Patients' responses focused mainly on healthcare providers' lack of knowledge and medical violence (11):

- 41% want to improve healthcare providers' knowledge and recognition of the disease; 26% want to end violence in the medical field; 25% want to improve care and support for endometriosis-specific issues.

Indeed, scientific knowledge also concerns health professionals who encounter difficulties in integrating this research into their medical practice. (12)



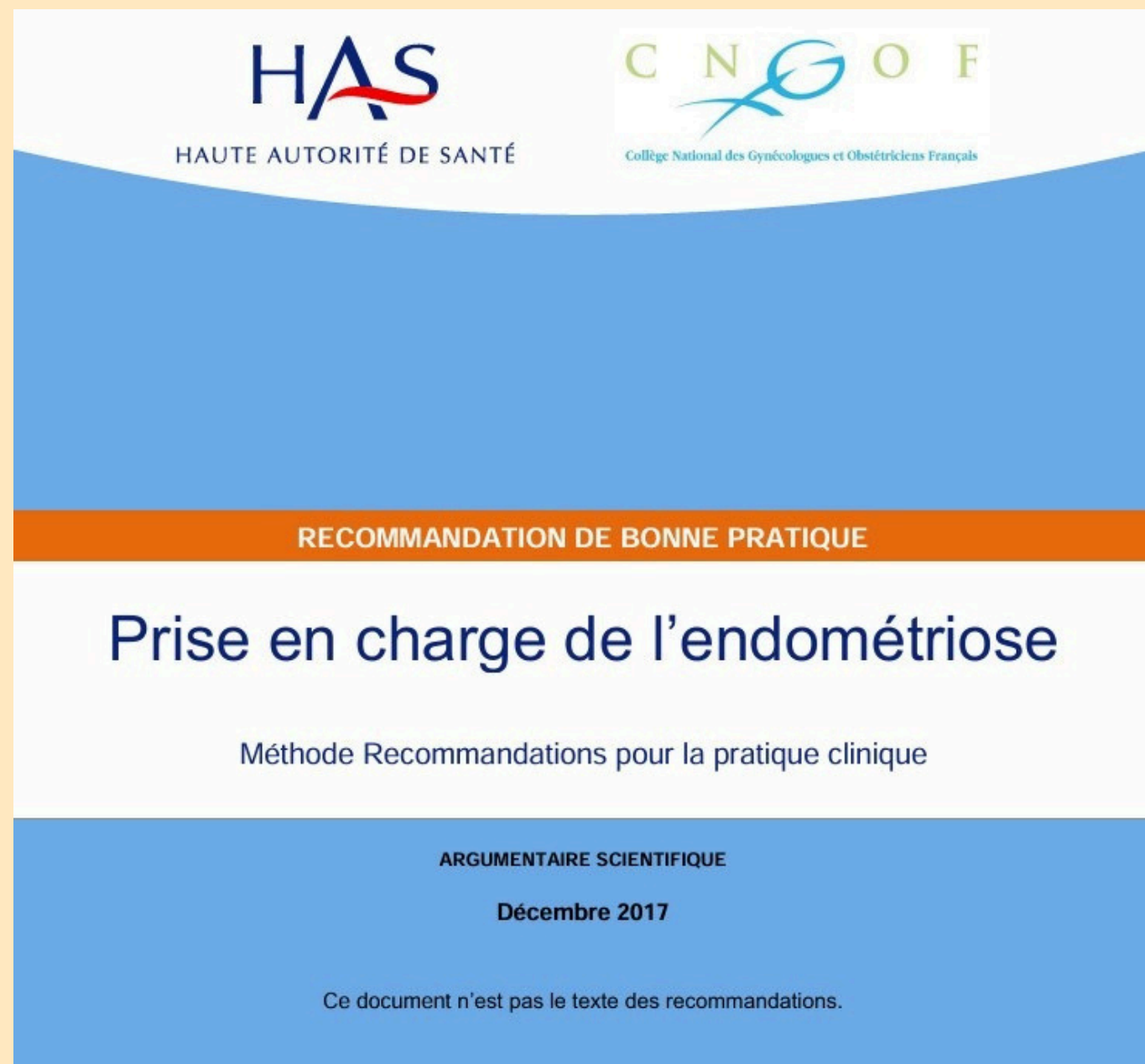


CHOICES IN THE STRUCTURED HEALTHCARE PATH





HEALTH CARE PATHWAY CHOICES OVERSEED BY THE HIGH HEALTH AUTHORITY IN FRANCE



In healthcare, clinical practice guidelines (CPGs) are defined as methodically developed proposals to help physicians and patients determine the most appropriate care in given clinical circumstances. CPGs are rigorous summaries of the current state of the art and available scientific data, described in their scientific justification.

They cannot exempt the health professional from exercising discernment in the care of the patient, which must be what he deems most appropriate, based on his own observations and the patient's preferences" (13)





MANAGEMENT OF CHOICES IN THE HEALTH JOURNEY IS ENCOURAGED.

Les professionnels de santé sont encouragés à sensibiliser les patientes à toutes les façons d'améliorer leur qualité de vie, sans se limiter aux thérapeutiques chirurgicales et médicamenteuses, en particulier par l'adaptation du style de vie et les thérapeutiques alternatives.

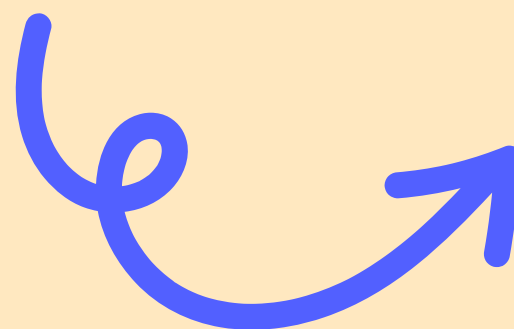
C'est la conclusion de sept études menées sur 61, 61, 30 et 20 patientes australiennes, 18 patientes néozélandaises, 30 patientes du Royaume-Uni et 13 patientes des États-Unis. Les preuves avancées comportent des limites majeures, ce qui confère à cette conclusion un niveau de preuve modéré (6, 7, 11, 14, 15, 23, 25)

Après avoir expérimenté les limites des traitements médicaux et chirurgicaux, de nombreuses femmes adoptent des changements importants de mode de vie, pour soulager et contrôler la douleur (5).

Dans l'étude de Huntington et Gilmour, la Fondation sur l'endométriose et le groupe de soutien ont été des sources d'informations clés qui ont permis d'ouvrir une gamme de modifications utiles au mode de vie. En effet, la plupart des femmes ont commenté l'insuffisance de l'information fournie par les professionnels de santé sur ce sujet. Augmenter le niveau d'exercice physique a également été jugé très utile par les patientes pour soulager la douleur et améliorer l'humeur. Des changements nutritionnels ont été adoptés par toutes, en mettant l'accent sur une alimentation saine, contenant une quantité importante de légumes et de fruits et éliminant les aliments à haute teneur en œstrogène. Les compléments alimentaires comme l'huile de lin et l'huile d'onagre ont également été préconisés par les patientes. Certaines femmes utilisent les herbes médicinales et de nombreuses femmes utilisent l'acupuncture (5).

« Je dois faire tous ces changements de mode de vie, c'est tout ce que je peux faire. C'est soit le suicide, soit je me lève et je me bats : faire des changements de mode de vie, prendre des médicaments pour aider si ça marche, demander de l'aide et admettre que je ne peux pas tout faire. »

Huntington and Gilmour, 2005 (5)



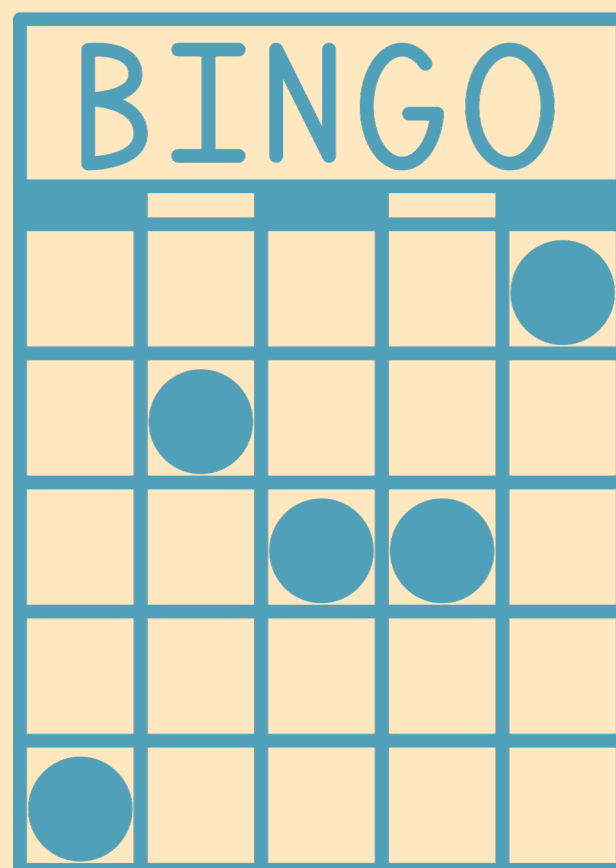
**THE CHOICE BELONGS TO THE PATIENT
(14)**

2 CHOICES IN THE HEALTH JOURNEY

Healthcare democracy is based on the active participation of patients in their own care journey and treatment choices. According to the scientific reasoning of the Higher Health Authority, there is currently no cure for endometriosis, but it is possible to obtain information and understand the available options in order to make an informed choice and become an active participant in their own treatment journey.

The main therapeutic methods currently offered by Western medicine to people suffering from endometriosis are allopathic and surgical treatments, as well as non-pharmacological interventions such as dietetics, osteopathy, etc.):

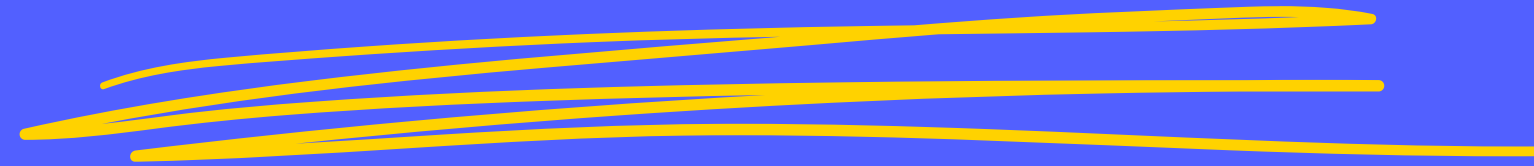
AESTHEOPATHY
HORMONE TREATMENTS
TO PHYTOTHERAPY
SPORTS ACTIVITIES



DIETETICS
IN SURGERY
PHYSIOTHERAPY
(ETC...)



THE THERAPEUTIC ALLIANCE



3 THE THERAPEUTIC ALLIANCE

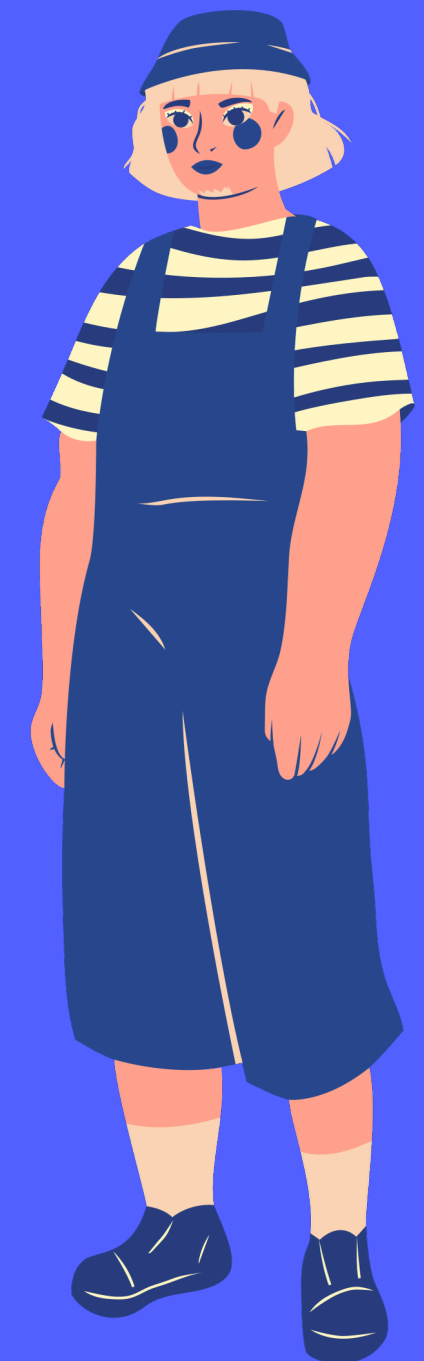
The Therapeutic Alliance (TA) is defined as "mutual collaboration, partnership, between the patient and his therapist to achieve the set goals". It is based on several principles such as trust and co-construction. In the context of endometriosis management: informed consent, pharmacovigilance and transparency regarding conflicts of interest are essential. (15)

MUTUAL TRUST



ACHIEVING GOALS

MUTUAL COLLABORATION



3 THE THERAPEUTIC ALLIANCE

CONSENT

NON
C'EST
NON

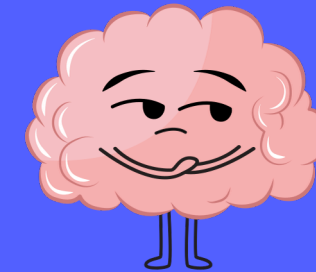
Consent is based on the patient's agreement at the time of the medical examination. (16) Without consent, it constitutes medical violence. Following 36 complaints filed against Dr. Daraï of the Tenon Hospital in Paris for "intentional violence" (17), a charter for gynecological consultations was signed by scientific societies to reiterate that "the woman's oral consent is obtained before any clinical examination" and that the procedure "must be capable of being interrupted as soon as the patient expresses the wish to do so." (18)

PHARMACOVIGILANCE



Pharmacovigilance involves informing patients about the risks, side effects and potential long-term consequences of drug treatments. (19) In the context of endometriosis, many women are now suffering from meningiomas as a result of various hormonal treatments such as Androcur, Luthenyl and Luthéran. This health scandal is the subject of a complaint lodged by the AMAVEA association. (20)

RISKS OF ASSOCIATED DISEASES



The risks of diseases associated with endometriosis must be communicated transparently to patients so that they can be aware of the multiple consequences of the disease. (21) Endometriosis and its treatments can increase the risk of cardiovascular diseases and require particular attention, since stroke still remains the leading cause of mortality in women. (22)

BE AN ACTIVE PARTICIPANT IN YOUR OWN HEALTH JOURNEY



CO-CONSTRUCTION OF
THERAPEUTIC GOALS

APPROPRIATION OF SCIENTIFIC
KNOWLEDGE

CREATING A THERAPEUTIC ALLIANCE
WITH TRUSTED HEALTHCARE
PROFESSIONALS

MAKE YOUR OWN
CHOICES

IDENTIFYING BELIEFS ABOUT
ENDOMETRIOSIS

KNOW YOUR RIGHTS AS A PATIENT

TO STAY UPDATED ON
SCIENTIFIC ADVANCEMENTS

WITH OR WITHOUT CONSENT DURING
TREATMENT

WANT TO KNOW MORE?



BREAK THE TABOOS ABOUT ENDOMETRIOSIS AND TALK ABOUT IT WITH THOSE AROUND YOU.

Talking about endometriosis and the scientific knowledge about the environmental causes of this disease allows us to break down the taboo surrounding menstruation and the beliefs related to blood, considered "responsible" for the disease. Spreading knowledge about the symptoms and the repercussions on daily life allows those close to us to better understand endometriosis. (23)



REPORT THE SEX THAT AFFECTS WOMEN WITH ENDOMETRIOSIS

Sexism related to endometriosis is an additional form of violence for patients that you can report when you meet with her. For example: "Because my partner has endometriosis, I am not as free as I would like; I would like to have sexual relations with other partners, and I feel that she asks me for more help than she needs." (24)



PROMOTE THE COMPLEMENTARITY OF SCIENTIFIC AND EXPERIENTIAL KNOWLEDGE

The recognition of the complementarity of knowledge in the healthcare field is based on the valorization of the experiential knowledge of those who live with endometriosis on a daily basis and who treat themselves every day to live better with this chronic disease. This experiential knowledge integrates the scientific knowledge that studies the understanding and functioning of the disease. (25)



BECOME A PATIENT PARTNER

Patient partners can engage in many forms of action; they can: teach future health professionals at university, share their experiences, collaborate on research with scientists, work within a health facility as a member of a team and participate in therapeutic education programmes for patients. In France, there are several training programmes dedicated to health partnerships. (26)

SOURCES

- (1) [Law No. 2002-303 of 4 March 2002 on patients' rights and the quality of the healthcare system \(1\) - Legifrance](#)
- (2) <https://presse.inserm.fr/cest-dans-lair/endometriose-les-projets-de-recherche-en-cours-a-linserm/>
- (3) <https://controverses.org/mode-demploi/>
- (4) <https://medialab.sciencespo.fr/equipe/thomas-tari/>
- (5) <https://www.lyv.app/le-mag/rencontre-avec-marina-kvaskoff-chercheuse-et-epidemiologiste-specialiste-de-lendomometriose>
- (6) <https://www.inserm.fr/portrait/laureat-prix-inserm/marina-kvaskoff-prix-science-et-societe-opicst-2023/>
- (7) https://www.medecinesciences.org/fr/articles/medsci/full_html/2022/03/msc200570/msc200570.html
- (8) <https://www.inrae.fr/actualites/approche-innovante-explorer-lien-entre-exposition-aux-polluants-chimiques-risque-dendomitrose>
- (9) <https://www.frm.org/fr/projets/bd-endometriose>



SOURCES

(10) <https://compare.aphp.fr/endometriose/>

(11) <https://compare.aphp.fr/2023/02/02/compare-endometriose-ameliorer-prise-charge-vue-patientes/>

(12) <https://www.sante.fr/endometriose/actualites/compare-endometriose-comment-ameliorer-la-prise-en-charge-du-point-de-vue-des-patients>

(13) https://www.has-sante.fr/upload/docs/application/pdf/2018-01/pris_en_charge_de_lendometriose_-_argumentaire.pdf

(14) https://www.legifrance.gouv.fr/codes/article_lc/LEGIARTI000031931654

(15) Bioy A, Bachelart M. The therapeutic alliance: history, research, and clinical perspectives. *Perspect Psy.* 2010;49(4):317-326

(16) https://www.legifrance.gouv.fr/codes/article_lc/LEGIARTI000031972276/2016-02-04#:~:text=Toute%20personne%20a%20le%20droit,choix%20et%20de%20leur%20gravit%C3%A9..

(17) https://www.lemonde.fr/societe/article/2022/11/24/le-gynecologue-emile-darai-mis-en-examen-pour-violences-volontaires-sur-trente-deux-femmes_6151448_3224.html

SOURCES

- (18) <https://cngof.fr/app/uploads/2022/12/Charte-de-consultation-en-gynecologie-et-obstetrique.pdf?x13417#:~:text=Les%20professionnels%20ont%20parfaitement%20conscience,bienveillance%20et%20de%20respect%20mutuel.>
- (19) <https://sante.gouv.fr/soins-et-maladies/medicaments/la-surveillance-des-medicaments/article/la-pharmacovigilance#:~:text=La%20pharmacovigilance%20a%20pour%20objet,la%20vie%20d%27un%20m%C3%A9dicament.>
- (20) <https://www.radiofrance.fr/franceinter/podcasts/secrets-d-info/secrets-d-info-du-samedi-09-novembre-2024-1225300>
- (21) <https://academic.oup.com/humupd/article/21/4/500/683602?login=false>
- (22) <https://presse.inserm.fr/l'accident-vasculaire-cerebral-une-autre-inegalite-homme-femme/29341/>
- (23) <https://sante.gouv.fr/IMG/pdf/strategie-endometriose.pdf>
- (24) <https://endofrance.org/wp-content/uploads/2020/06/resultat-enquete.pdf>
- (25) https://www.has-sante.fr/upload/docs/application/pdf/2023-11/has-109-note_de_cadrage_experience_patient.pdf
- (26) https://www.patientpartner.org/files/Communication_17_fr.pdf

READ, WATCH, LISTEN

ENDOMETRIOSIS: THE SEXIST LEGACY OF A DISEASE THAT HAS CAUSED PAIN SINCE ANTIQUITY FRANCE INTER

<https://www.radiofrance.fr/franceinter/endometriose-l-heritage-sexiste-d-une-maladie-qui-fait-mal-depuis-l-antiquite-8767441>

"THE GHOSTS OF HYSTERIA - THE STORY OF A CONFISCATED WORD" EPISODE 1/4: THE MATRIX OF EVIL FRANCE CULTURE

<https://www.radiofrance.fr/franceculture/podcasts/lsd-la-serie-documentaire/la-matrice-du-mal-1152323>

THE GYNECOLOGIST AND THE WITCH ART RADIO

https://www.arteradio.com/son/61659783/le_gynecologue_et_la_sorciera

THE AUGSBURG OATH: WHAT IF WE REBORN THE CAREGIVER RELATIONSHIP? A PODCAST FROM THE SORBONNE NOUVELLE AND THE APHP

<https://lesermentdaugusta.com/>



READ, WATCH, LISTEN



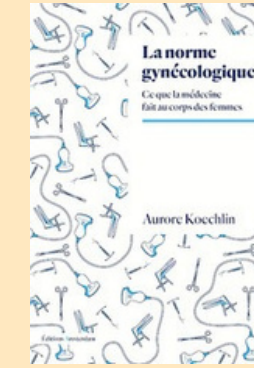
THE TEST OF KNOWLEDGE – PROPOSALS FOR AN ECOLOGY OF DIAGNOSTICS

Katrin Solhdju, 2015



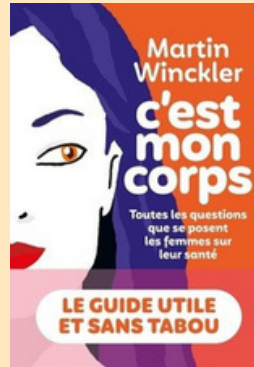
HEALTHY DEMOCRACY

Christian Saout,
2022



THE GYNECOLOGICAL STANDARD

Aurore Koechlin, 2022



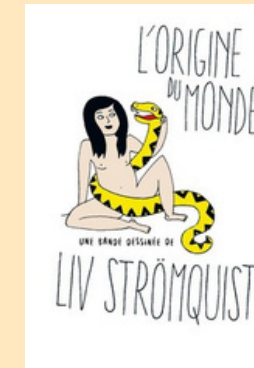
THIS IS MY BODY

Martin Winckler, 2020



OUR BODIES, OURSELVES

Mathilde BLEZAT, Naiké Desquesnes,
Mounia El Kotni, Nina Faure, Nathy Fofana,
Hélène de Gunzboug, Marie Hermann,
Nana Kinski, Yéléna Perret, 2020



THE ORIGIN OF THE WORLD

Liv Stromquist, 2016



ALL ABOUT ENDOMETRIOSIS

DRLhuillery,DRPETIT,DRSauvanet, 2019



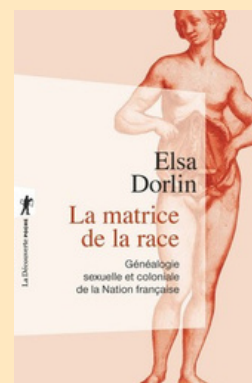
THE ANTI-ENDOMETRIOSIS DIET: THE ANTI-INFLAMMATORY DIET TO COMBAT PAIN.

Fabien Piasco, 2019



LET GO OF OUR UTERUS

Fiona Schmidt, 2020



AT THE MATRIX OF THE RACE

ELSA DORLIN, 2009

READ, WATCH, LISTEN



ON THE ENVIRONMENTAL PATH

Madeleine Akrich, Yannick Barthe and Catherine Rémy, 2010



MOBILIZATION FOR HEALTH

Madeleine Akrich, Yannick Barthe and Catherine Rémy, 2009



MANIFESTO FOR NARRATIVE MEDICINE

Isabelle Galichon, 2024



HUMAN STUDIES IN MEDICINE

Cécile Lefère, François Thoreau, Alexis Zimmer, 2020



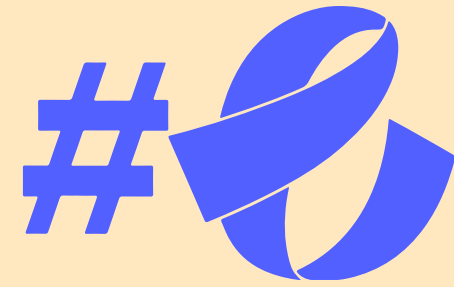
PATIENT COMMITMENT TO THE HEALTHCARE SYSTEM

Olivia Gross, 2017



FRAGILE OR CONTAGIOUS

Barbara Ehrenreich and Deirdre English, 1973



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A training program offered by MaëliSS Le Bricon with the Endometriosis Academy as part of the European #ENDO project.

Since 2020, MaëliSS has been conducting research as part of the artistic, scientific, and political experiment "Where to Land?", led by philosopher Bruno Latour with a multidisciplinary consortium. Using a compass, she is invited to map all the elements that support or threaten her health journey. Drawing on her personal experience, she examines the work of scientists, trains at the University of Bordeaux to teach medical students as a "patient educator," and deepens her understanding of the disease to lead therapeutic education programs for patients at the Clinique Mutualiste in Pessac. MaëliSS is currently pursuing her research collectively with projects from the Endometriosis Academy, with the support of Creative Agency, and through a co-research project with the Workshops of the Days to Come. In 2024, she was invited to share her work in the form of a participatory performance at the BAG Gallery in Bordeaux as part of the exhibition BREAKING THE SILENCE. As part of the European ENDO project, she is sharing the results of this research to enrich the training program for people with endometriosis.

