WE ARE 200 MILLION

CODE NAME
ENDOMETRIOSIS

A DOCUMENTARY
of AYNOA
in collaboration with
Marianne BP and Amit K.Babooa

SUMMARY

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We are 200 million people - Code Name Endometriosis is a Documentary which aim **to show the impact endometriosis has in women's lives worldwide, through their testimonials.**

Identified in 1860, the disease has only begun to come to light in the last few years. But, despite the sudden interest of the media, it is still taboo, misunderstood, poorly cared for and the women affected still suffer a lot of injustice.

There are as many endometriosis types as there are women! There are thousands of stories to be told! Endometriosis affects 1 to 2 women out of 10 worldwide, or 200 million women, girls, teenage girls.

Whatever their language, their ethnicity, their age, social condition, religion, they all speak the same language.

The documentary aims to represent each type of endometriosis, each story and also show the similarities between women wherever they are located in the world.

From Paris to Geneva, from Tunis to Kenya, from Quebec to London, despite their differences, they have in common the experience of injustice, delays in diagnosis, the medical wandering, the lack of a cure, physical/moral suffering.

They also share their hopes and strengths. Each story is a mirror for another. Their names are Ines, Zoubeida, Magdalena, Nishani etc..., they come from the 4 continents and 21 different countries.
They respond to a call for testimony, and, through the same survey received, they record themselves and, with an open heart, share their experiences their daily life, their medical, social, intimate experience, with the disease.

From the first periods to today, going through the pre-diagnosis, the diagnosis, after diagnosis.

The film is for everyone: people living with endometriosis, people in the medical field, family and friends, public authorities, national and international audiences, to help raising awareness, for a better understanding of the disease, and bring even more action.

So much is missing: funds for the research, training of our doctors, improvement of the care for endo, screening, a cure.

NOTE OF INTENT

I had a visceral urge to talk to these women, to let these women speak up, to listen to them, and that they could be heard.

I am one of them. And like them, I was an affected teenager then, too.

In 2014, they made themselves heard all together for the first time. It was initiated by Dr. Nezhat, an American who created the Million Woman March for Endo, which became Endomarch.
Ever since, each year, on the same day in March, women from 50 different countries are marching to ask for help.
Posters describe the pain largely ignored by the medical profession: "Worse than childbirth".

We are no longer alone. We are thousands to experience the same tragedies.

Diagnosed a month later, I discovered with amazement a new word, and I suffered the full impact in a medical desert for one whole year, 2 years of agony without real care, on a road paved with ignorance and contempt.

In 2015, I decided to commit to this cause through my art. **I am an author, composer, and performer.**

I meet Marianne BP, a video artist, who joined me to realize two projects for endometriosis in 2016 and in 2019 in support of the Endomind association.

Resilience. I live a nightmare in Paris. How is it in the rest of the world?
Society, the medical profession, our families, have a hard time believing us, I express the vital need to say to them: Listen!

We are 200 million affected women in the world and what if we were united for the same project to bear testimony?
As a member and supporter of the association ENDOmind, I get in touch with **Nathalie Clary*** in February 2020, ENDOmind's president, who assures me of her immediate support by relaying the call for testimonials on facebook. Then we are joined by **Mems, Endometriose Quebec, Endometriosis Association of Ireland, Endopolynésie, Fundacja Pkonac Endometrioze, Associaçao portuguesa de Apoio a mulheres com Endometriose, Myendosis Malaisie, Karuk endo Guadeloupe, EndofiGabon, Endosisters East Africa, Endometriosis South Coast, Endo Israel, EndoSmile Côte d'ivoire, The Endometriosis Network Canada as well as many groups on facebook, blogs or organizations such as Pelvic Pain India, Endometriose mon Amour, Endometioza y ja etc...**

I receive hundreds of emails, it's a flood of testimonials from all over the world.

I question.

Endometriosis, left untreated for years, literally crippled me and plunged me
in a very precarious situation.
Echoing my own story, women who send me their videos speak about the impact on their lives professional, social, intimate.

And if we all together made aware everybody to get better recognition, rights, a universal conscience? Is our own word not our best ally to act for "the disease of silence"?

What is endometriosis?
"It's a chronic disease, typically recurrent, which can be very debilitating. Multifactorial, it is are the result of a combination of genetic and environmental factors and related to menstruation." It is characterized by the presence of tissue, similar to the endometrium but outside the uterine cavity. These endometriotic cells react to hormonal fluctuations during the menstrual cycle, bleed and, unable to be evacuated naturally, cause lesions, nodules, cysts, and cause adhesions between organs that prevent their good movement and proper function.

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*On febuary 2022, Céline FERRARA becomes the new president

The statements of We are 200 million - the code name for endometriosis, will bring enlightenment and help eradicate the minimization, the prejudices clouding the disease, and bring awareness of endometriosis in order to continue work on a better care.

• A progressive disease

In France, the recommendations of the Haute Autorité for Endometriosis revised in 2020 shortly before that I write his lines, still contains gross errors: it states in particular that "the data is not support the progression of endometriosis over time, and that in the absence of symptoms, it is not recommended to offer systematic screening".
It is indicated that "there is no data to justify or organize a screening of the general population for endometriosis".

From my own medical background, these guidelines make no sense and this is one of the reasons that prompted me to do this documentary, and to question those women, to just precisely collect data proving the contrary.

It is crucial and urgent that the medical profession recognizez that this is a disease that can be widely progressive and recurrent so that mandatory screening should be instituted from the first menstration onward, with or without symptoms, and regularly.
It will prevent the anarchical progressions, will save organs, and a better conservation of female fertility.
In February 2022, a revolutionary news arrives that I am happy to add to this dossier: an Endotest saliva test), developed by Ziwig, is validated by the largest clinical study in the world.

Because it is not well known, it will also be important to show through testimonials that this disease can migrate throughout the body and thus affect several medical disciplines such as urology, pulmonology, and gastroenterology.

Some, like Anne-Sophie, are sick since they are 9 years old. **Those are years without treatment and the disease progresses.**
The testimonials in the film will help shed a light on this emergency: Emeline had a piece of her intestine removed and nearly lost a kidney, Katty can no longer use her bladder, Nathalie who lives in Belgium, has endometriosis that has spread into her lungs and suffers pneumothorax each and every month.

• A taboo disease

Barely 3 years ago, no one had heard of endometriosis. Despite the progress in terms awareness and treatment, the situation remains very fragile.

Still many doctors ignore and despise endometriosis, there is still a certain medical misogyny on the part of men and women.

When the diagnosis is announced, these women who are forced to suffer in silence and to be quiet about the infinite taboo surrounding menstruation, see themselves rejected and blamed for it again: "It’s hip". You talk too much about it.

A year ago I saw a gynecologist to whom I expressed my joy at this new attention for endometriosis. He, however, lamented that now "a whole bunch of teenies came to his office because they wanted to know if they were affected"... In Malaysia, **Surita Mogan,** founder of **Myendosis**, claims that no one speaks about period pains because it is considered taboo. They think the women should "bite their tongue and suffer, and that they should endure the pain. If they speak about it, everybody believes they are exaggerating".
Little girls grow up with this belief that it is normal to agonize every month and they must remain silent. This medical and societal abuse must stop.

How can one hope for the better, when the health authority also indicates in its new guidelines concerning endometriosis, sent to all doctors in France, that women feeling pain have hyperalgesia.
The definition of Larousse dictionnary states: "Exaggeration of painful sensitivity". We go back in time to the saying: "it is in your head" on which we were raised. This is unacceptable. The documentary reveals this ubiquitous abuse, across all generations.

Once the diagnosis is pronounced, we see our life in fast reverse. It is a real turmoil. Being able to speak up is a deep breath of oxygen, it is an enormous freedom.

***We are 200 million - code name endometriosis - shows that the taboo around menstruation is universal.**
However, it is clear that speech is not equally free everywhere. There are some countries that I couldn't contact, because its culture does not allow at all that women express themselves. Nishani, a Sri Lankan expatriate in Canada, testifies in the film and explains to me, voice only, that it would be extremely difficult to obtain a testimony from any local woman. She clarifies to me that in Sri Lanka women talk very little about their period, even to their doctors.

An Algerian woman also explains to me that she wishes to testify but with her face covered because her family and her husband are totally unaware, then finally she rescinds.

• A bit of history:

Actions for endometriosis.
Since 2017, there have been immense advances for endometriosis. The first mission was to bring it into the limelight and tell the whole world: "a disease that you don't even know affects 200 million women in the world". We ourselves didn't even know about its existence before a diagnosis. Then we started to work for the improvement of an almost non-existing treatment of the disease.
In France, associations, patients, celebrities, and doctors mobilized.
The different ministries of health became involved.
For example, there was an endometriosis plan in order to raise awareness in the school infirmaries, with the teachers, the creation of Compare in 2017, a research project around chronic diseases and especially endometriosis.

This year, an ARS Ile-de-France call for projects, supported by ENDOmind, took place for the formation of treatment centers across the nation in order to shorten diagnostic delay and to propose a treatment strategy and to avoid meandering. Finally, a campaign started, run by Endomind, to enter endometriosis into the list of ALD 30.

In October 2020, endometriosis finally entered the medical school curriculum.

January 2022, President E.Macron announces the implementation of a national strategy for endometriosis, but the disease still does not enter the list of Ald 30
despite the vote of the National Assembly.

What about in other countries?
Italy is considering to adopt a leave of absence for women with painful periods, and established an emergency number, because the pain can be so tormenting and violent.
The Australian government has publicly apologized for not having spent a single euro on research to this date, like we did, and officially appropriated $ 4.7 million for the first action plan against endometriosis.
Associations are emerging around the world, Endometriosis Quebec was created in 2015 by Marie-Josée Thibert, Myendosis in 2013 in Malaysia, Endofigabon in 2018, The endometriosis Network Canada in 2012 etc... and they promote awareness with conferences, campaigns in schools etc.

In Canada, the B.C. Women's Hospital (first center dedicated to endometriosis) has launched an awareness-raising program

endometriosis in schools in the New Westminster area: it is based on a school course developed by Endometriosis New Zealand, which had shown positive results after early detection plus treatment.
The hour-long interactive session focus on different topics and allows young people to monitor their symptoms and give themselves the means to seek help.
In 2019, the Clínicas hospital in Uruguay, opened the first diagnostic unit and the treatment of chronic pelvic pain, and endometriosis in women, which is open to all users of the administration of the state health services (ASSE).

The Israel Endometriosis Association and the National Insurance Institute collaborated to see the birth of a guideline designed for endometriosis specialists that will facilitate the administrative procedures to obtain the recognition as a disabled person.

In October 2020, Standart Group PLC partners with Endo Sisters East Africa Foundation through the Great Places to school initiative, to create an impact in the lives of schoolgirls in Kenya, on the issue of the menstrual disorders.
The world is on the move to awaken consciousness and to give rights for this disease ignored for too long.
However, despite the recent spotlight on endometriosis, despite the massive advances, much remains to be done.
The documentary will keep a universal look on disease management and highlights the shortcomings and the improvements that can be made. Treatment is difficult everywhere and can be dramatic or even non-existent.
Finally, giving a voice to women in the whole world is for me a chance to be able to draw inspiration from one another, and to support each other. Joined by Marianne BP, I wanted this documentary to be a chance to talk to each other, to share our hopes, our ideas, our positive force.

My life mission is to ensure that future generations do not have to experience what we had to live through.

One might think that this happens in faraway places like the Amazon or in developing countries around the world.

No. The testimonials in the film decry enormous delays everywhere.
I had to wait 19 years, I lived in Puteaux in France, a rather cozy suburb 2 steps away from the Business Area "La Defense", and my gynecologist lived in the rue de Rivoli, Paris 8th district.

For Marie-Michelle, in Quebec, the wait was 15 years, just like for Julie from France; Leah in the United States had to wait 17 years.
They are 29, 30 and 32 years old.

BEATRIZ
SPAIN

MELODY
FRANCE

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NISHANI
SRI LANKA / CANADA

SARAI
MEXICO

DIRECTOR'S NOTE

Self interviews in the documentary are inspired by the films of Yann-Artus-Bertrand Human and Woman. Women film themselves in front of camera, in landscape format.

It's a huge interview. For each question, there are multiple answers from women living with the disease, of any origin, age, country.

If we had advocated a plain background or nature, some of them have largely taken the freedom to film themselves wherever they want, and this diversity brings authenticity.

So Sarai will ask a friend to film her in the middle of the street in Mexico, Susan in a large shed in Kenya, Doris in a primary school, Pela in her living room in Greece etc... So here we are sometimes with a background of birds, horns, lapdogs, and crying babies.

Technical imperfections become a fabulous journey as you go along, and lead to a real concept.
We are going to go around the world, with language, landscapes, noises, sounds, the different personalities, colours. Each offers a little bit of herself and one becomes terribly attached to those women who give the hand one another, to form one same family.

Sometimes one is interviewed by her husband, another by her son, others will be alone, other one will only choose to answer.

The documentary is devoid of comments, they are the ones who speak, we enter totally into their intimacy, in their history.

Answering the questions, they give themselves up, with sincerity and amazing naturalness. They share beauty, distress, anger, optimism, hope, strength, reflection, love, sorrow, humour, tenderness.
Each woman was free to respond to the questions of her choice.
They also had the opportunity to speak in their native language.

The documentary is available in 6 different languages.

A multimedia project will be set up for the launch of We are 200 million, Code Name Endometriosis, via the string youtube and the project's social networks, we will initiate image portraits and also the shares of some interviews in their entirety.
Mini-Videos per theme, approx. 1 min, will also be published.
A trailer also accompanies the project.

The documentary and each media will have 2 versions: one with French subtitles and one in English so that everyone can understand.

The music

In order to illustrate moments of silence or in the background, I chose to propose my compositions among which:
- **I have a volcano in my belly** (arranged in collaboration with **No Pink**).
- **We were told it was normal**, as a duet reading with the actress **Noémie de Lattre**.
- **Prayers**
- **We are one out of ten** , a song especially written for the project.

I also propose to my friend **Edgar Sekloka**, former member of the Milk Group Coffee Sugar in duo with Gael Faye. He writes for the project "**En te servir du Thé**" one wonderful text about and for women, on the **NKZ**'s Sky product.
Joining us, **Sarah Mathon** and her poem "**Their bellies bleed"**.

• Medical guesswork

We might think that in the 21st century, after a such delayed diagnosis, the patient is immediately taken care of. However, the testimonials in **We are 200 million - code name endometriosis, testify to the contrary.**

Sarai in Mexico was looking for a specialist for 3 years and is still searching. Fourteen years after her diagnosis, Beatriz from Spain finally got an appointment with a specialist. Margaux in France said she did not roam for long after she has been through 9 gynecologists...
Susana Fonseca, President of **Muhlerendo Assoçiacào** in Portugal, had to wait 1 year after her diagnosis to receive coverage because health insurance did not approve of the required surgery.

Just like Marie, who for 3 years, went to "specialists" who were not convinced and did not explain anything to her.
If they only would have!

The medical meandering until the announcement of a diagnosis concerns all countries, but some have to face an even more dramatic journey.

Irène Pegha Moukandja, doctor in tropical infectiology, and in charge of the association's scientific committee **EndofiGabon**, was one of the first to present her testimony.
She told us that she went to Morocco for treatment, and all medical care was billed.

While some countries have very few specialists, others have only one or two.

Zoubeida indicated that in Tunisia, there is no center dedicated to endometriosis.

In France, the endometriosis center of Hospital St Joseph in Paris, receives patients from all over France and the waiting list is months long.

Leah Battista told us how lucky she was to wait only a month to find the **Center for Endometriosis Care in Atlanta,** Georgia. Marie-Rose Galès, founder of "Endometriosis my love", indicated that she had to assemble her own medical team to have a real follow-up.

• There is Psychological violence

sometimes from an early age on caused by the medical profession and society:
"It's all in your head", "It's normal"
For 8 years Solenn, 21, who lives in Brittany, was told that it is psychological and she was prescribed a psychotropic drug as a treatment.
It means growing up with diminished, erroneous self-esteem.
"One of my general practitioners, confronted with my frequent urinary tract infections, has ended up telling me that I was dirty" confided Marie.
"At that time the gastroenterologist had prescribed anxiolytics" said France.
"When I was young and going throught this pain, the doctor said to me, well if you can't even handle a simple period, how will you carry a pregnancy ?" So strong were humiliation and guilt that **Doris Murimi,** president of **Endo Sisters East Africa Foundation**, thought as a young woman that she was weak.

Thousands of young girls grow up with this feeling, this trauma.

The injustice is immense. Because in fact, they are supernatural to be able to support the often inhuman symptoms. They are called endowarriors.

• Physical suffering

Wherever the country, the terms to describe pain, the primary symptom, from one language to another, are always the same: blades, swords, stabs, needles that pierce, electrocuting electricity, steam rollers that crush everything in their path.

FLORENTA, 30 years old, Switzerland: "In those moments, I really believed that I was going to die, that there was no way out and my stomach was going to blow up. »
LEAH, 32, USA: "It's like the inside of my body was on fire, and that I was endlessly stabbed, or that an elephant was sitting on my chest. "

• A complex disease

Through these testimonials we wanted to represent all shades of endometriosis.
It is a very complex disease and it is high time that the governments commit funds to its research. The disease begins as early

as the first periods, most girls have pain immediately, but others not necessarily. For example, there are women who developed symptoms three years later.

As the disease progresses along comes an evolution of symptoms.
Many at the beginning have pain, "only" during menstruation. Then, years later, they suffer on a daily bases because lesions, cysts, nodules, and adhesions that developed.
PELA, 39, from Greece: "... a few years later the pain changed, became more aggressive, deeper. I felt as if I was suffocating."
INES, 22 years old, France, had just been

JENNIFER
25 | SPAIN/SWISS
Saleswoman/Decorator

"To believe for moments that it's the end, that I'm going to die from such great pain even to the point of almost losing consciousness."

"Croire par moment, que c'est la fin, que je vais mourir d'une si grande douleur, au point de perdre quasiment conscience."


ALICIA
URUGUAY


IRENE
GABON

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MAGDALENA
POLOGNE/ENGLAND


LEAH
USA

diagnosed when she joined the project during lock-down. She confided in us that she has asymptomatic endometriosis, which means she never has had pain, not even during her period.
Nevertheless, for two years now she developed an ill recognized symptom yet common in endometriosis: dyspareunia (painful intercourse), and "thanks" to this symptom, she obtained a diagnosis.

There are women who do not develop any symptoms at all, but that does not mean they are not mutilated internally and the disease does not progress.

These forms are no less important, because they are so devious, and we realize that they can evolve into symptomatic forms.

The symptoms are diverse and not necessarily indicative of the stage of the disease. They can also depend heavily on where the lesions are located.
Superficial endometriosis can be very painful, even disabling and at the same time a deep endometriosis passes unnoticed.

Each woman has her own symptoms and every woman has her own endometriosis.

Women reported about possible symptoms, which are far from commonly known by society and the medical profession.
- Dysmenorrhea: menstrual cramps, pain in the lower back, in the thighs.
- Dysuria: pain and urinary incontinence.
- Dyschezia: Painful bowel movement, alternating constipation and diarrhea, bloating, intestinal cramps.
- Pelvic pain: uterine contractions, pain in the ovaries.
- Lumbar pain: sciatica, especially in case of lesions of the uterosacral ligaments, low back pain, back and shoulder pain, diaphragm compression.
- Headaches: migraines.
- Nausea, vomiting.
- Asthenia: Chronic fatigue, feeling exhausted, heaviness of the body.
- Collapse: sudden discomfort, accompanied by a drop in blood pressure.
- Infertility.

• Impact on the professional life, social, or intimate

ALICIA, 37 years old, Uruguay
"I had to take a lot of sick leave. It delayed the completion of my professional goals, my studies and my job. (...)
I can't help but think of other women or people in my situation and with other working conditions and the truly dramatic consequences that may result in not being able to keep a steady job."
MARIA CARO, 35, Chile
"Endometriosis has a profound professional impact because you have to consider that there are times when you cannot get up, times when it is difficult to walk."
MARIE, 35 years old, France
“It takes friends with patience. What has been scheduled may be canceled at the last moment, because we bend over backwards in the toilets ... "

NATHALIE P, 29, Switzerland
"I have pain during intercourse, sometimes I do, sometimes I don't."
LEAH, 32, USA
"It wasn't just during the intercourse, but hours later, and sometimes even days later. I had to decide if it was worth the pain for 2 or 3 days after having had intercourse."

We are 200 million - code name endometriosis questions what women expect from IMPROVED CARE. They all agree:

• Physician training

Endometriosis is little or not at all taught in medical school.

HELOISE, 32 years old, France

"It would already be necessary that gynecologists are trained and informed, because of numerous gynecologists who tell you "you don't have anything, it's in your head", "you have to deal with the pain", or now we hear gynecologists who tell us "don't tell me it's this disease en vogue, endometriosis. That there is also education in teaching facilities to take away the feeling of guilt from these young girls, who suffer and who hear nothing but "it's in your head."

Ultrasound specialists, radiologists ignore the disease for lack of training which further delays diagnosis.
It is also important to train general practitioners as well as the entire medical profession, as the disease can concern the whole body.

• Rights

EMELINE, 30 years old, France

"Recognize more easily the status of a disabled worker, with a chronic preexisting condition, sick-leave too, when we are unable to work 2, 3 days a month, that we cannot go to work because we are in the emergency room getting a morphine infusion."

PELA, 40 years old, Greece

"I would recommend that we can benefit from free psychological help; that would be a good idea. "

MARIA CAROLINA, 35, Chile

“In Chile, it is very difficult to obtain aid from the state when you are middle-class... Endometriosis is not a disease that fits into

KATTY

37 | FRANCE

"I think it should just be taught during the medical studies so that diagnoses can be made quickly with a personalized accompaniment."

"Je pense qu'elle devrait juste être enseignée en médecine de façon à ce que les diagnostics soient fait de façon rapide avec un accompagnement personnalisé"

any health plan."

Endometriosis has a tremendous impact on the professional life of women.
In most countries, access to healthcare is not free of charge, so many young girls cannot be diagnosed or treated.

In France, to benefit from 100% free care, you have to make a request of an unlisted chronic preexisting conditions, because endometriosis is not yet included.

I have asked for help twice and I got two refusals. I had to make a clemency plea in order to obtain the right, in 2016. This takes months of battle, while we can hardly stand up.

- **Improvement of the care for endometriosis**

BEATRIZ, 39, Spain
"They should first train specialists and coordinated teams of different specialists (urologist, gastroenterologist gynecologist, physiotherapist ...) that work together.
Give comprehensive information (symptoms, causes, treatments, diets, food, because diets have a great influence, physiotherapy)."

JULIE, 30 years old, France
“Before I was diagnosed, I saw gynecologists, gastroenterologists, and no one was able

to make the connection between different symptoms and different organs. When it is multidisciplinary, everybody is passing the buck, a real connection is missing."

Endometriosis can affect all organs in a body.

NATHALIE, 45 years old, Belgium, has thoracic endometriosis, in the diaphragm and the pelvis.
MARIE MICHELLE, 29 years old, Quebec, has bladder and intestinal endometriosis.
SUSAN, 46 years old, Kenya, has adenomyosis, a form of endometriosis inside the uterine muscle.
NISHANI, 42 years old, Canada/Sri Lanka, has digestive and ovarian endometriosis.
JULIE, 30 years old, France has affected nerfs, etc.

- **Early detection**

IRENE, 35 years old, Gabon: "To diagnose it very early in young girls before any damage may ensue."
LEAH, 32 years old, USA: "One measure to improve medical care and delay until diagnosis would be to have a questionnaire that general practitioners or gynecologists would give their patients, in order to assess the risk of suffering from endometriosis. "
I also think that there should be a screening protocol in place with mandatory ultrasound from the very onset of the period.
Left for years without treatment, the disease will spread and damage the body.
Early detection may also allow to better study the disease.
If we understand endometriosis better in the future, adolescent girls will be diagnosed

KATELL
41 | FRANCE
Legal writer
"That it doesn't affect my daughter that it doesn't affect so many children..."
"Que ça ne touche pas ma fille, que ça ne touche pas tant d'enfants... "

earlier because their symptoms will then be taken into account.

What will happen to those with an asymptomatic form? How many years will they have to wait? Or if they do not develop any symptoms, they will continue to be diagnosed by chance, during an infertility consultation, with an already damaged body?

• Better listening, just listen!

ALICIA, 37 years old, Uruguay: "I think the first thing to do is to listen, to really listen. "

MARIA CARO, 35 years old, Chile: “You have to think that many women live with the symptoms but don't know that they are affected and the main idea is that people who work in the medical community listen to you, offer empathy and gradually help you find your diagnosis."

MAGDALENA, 40 years old, Poland/ England: "... because the doctor had decided that it was impossible to feel such an intense pain."

Lack of listening contributes to the delay of a diagnostic.

• A cure

MONICA, 41 years old, Argentina: "That one day this disappears from my body."

MARIE MICHELLE, 29 years old, Quebec: “My biggest hope is that research will be put in place. Let it not just be a medication to eliminate symptoms but find a cure. I hope to live enough longer to see this in my life."

Currently there is no cure for endometriosis.

• The "Treatments"

SARAI

29 | MEXICO

Architect

"Well, I hope that science advances in such a way that it can find an effective treatment and that women's organs and reproductive systems do not have to be lost."

"J'espère que la science progresse de telle manière qu'elle puisse trouver un traitement efficace et que les organes et le système reproductif des femmes n'aient pas à être perdus."

Hormone therapy and/or surgery?
How far are we? Is there any real efficiency? What are the side effects of the treatments? Hormone therapy and artificial menopause, can reduce the symptoms and disease progression, in exchange for eerie side effects. But at what price?
MELODIE, 31 years old, France: "... for two years I tried everything.
It took two years to find Androcure which I took for eight years and this summer I received a letter from social security saying the treatment was going to be suspended because potentially dangerous,
(...) the closest replacement drug was out of stock this summer...."

... The Lutéran, which one year later was also considered as causing brain tumors...

This is the 3rd "treatment" considered dangerous in France.
For some surgery is essential but we learned that the disease reappears very quickly with even stronger symptoms in many testimonies. The side effects can also be very severe.

Marie-Michelle from Quebec lost control of her bladder, just like Claire in France.
For some women, surgery helps before a PMA treatment. For others, surgery compromises fertility.

Following a partial hysterectomy for her pelvic endometriosis, the Belgian Nathalie G began to suffer repeatedly from pneumothorax with pain in her shoulder.
It followed a thorascopy and an abdominal laparoscopy which confirmed a diagnosis of thoracic and diaphragmatic endometriosis, with holes in the diaphragm and a clogged liver!
These holes are caused by the nodules of endometriosis lesions.

We also interviewed women on alternative medicines, these precious allies.
They shared their experiences with us, especially with: osteopathy, yoga, or herbal medicine...

• Maternity

While 40% of women encounter fertility problems, the other 60% do not.
It all depends on the severity of the symptoms, on their age.
Pela gave us her testimony as a mother having delivered her three children naturally.
Mylène from France still has no children. She has been on fertility treatment for 8 years.
France has never managed to get her 2nd, so much desired child, Anitouké experienced her little miracle naturally during her fertility treatment.

AYNOA

www.aynoamusic.com

Author, composer, performer and actress.
In 2014, Aynoa was diagnosed with endometriosis after a delay of 19 years.
In 2015, she contacted Marie-Anne Mormina who was in charge of second worldwide march against endometriosis, and she proposed to sing during the closing ceremony.
Aynoa sang, for the first time, "Prayers", a song written in 2007 in support of a friend under fertility treatment.
Thanks to the march, Aynoa met Nathaly Clary who had just founded the association ENDOmind as well as Imany, it's amazing godmother.

In 2017 she released a first EP and donated the sales revenue to the ENDOmind association.
In the same year, she sang for the 10-year anniversary of the Endometriosis Center of the hostpital St Joseph in Paris and at the Pas Si Sage Party in Monaco, where the association participated.
She also performed at the Grimaldi Forum in Monaco to inaugurate the “Seen with the Heart” conference by Yann-Artus Bertrand.
The music video of the song "Prayers" was financed by crowdfunding on the Internet platform "One donation for one project" of the ENDOmind site.
It was directed by Marianne BP who in 2019 also realized the video "We were told that it was normal", a poem by Aynoa read together with the actress Noémie de Lattre.

MARIANNE BP

https://www.initialbp.com/fashion
http://www.mariannebp.com/

Poet, author, performer and video artist.
Marianne BP released her first EP in 2017 entitled "Aparté parisienne" as well as her first novel "Rose Ascendant Pourpre" as a self-published book.
Marianne BP expresses her views intertwining images and words.
Her style sails between shocks, ruptures and sensitiveness. This openness and particular compassion she has also put at the service of others with initials BP, the production company she directs, and in collaboration with Guillaume Saix, a graphic designer.
She assured the production of clips for Aynoa, Robyn Bennett, John Banzai, Komo Sarkani etc, and of live sessions serving the renowned Parisian jazz scene: Joel Hierrezuelo, Munir Hossn, Mario Canonge as well as "Video fashions": Béatrice Dalle, Peplv Magazine etc.

AMIT K. BABOOA

www.instagram.com/amitkbabooa

Director and post-producer since 2010, Amit Babooa signed many film direction both in the short film, advertising or video clips (Yael Naim).
His CV includes about twenty awards in several festivals. In particular price for the best series at the Festival de Luchon ("Valentine and Me").

CREDITS

LINKS

https://twitter.com/WEndometriosis

https://www.facebook.com/Weare200million

https://www.instagram.com/weare200million

https://bit.ly/35kCery

Trailer
https://youtu.be/XMVpltdMKt4
Clip Prières
https://youtu.be/Ns152QqkIIA
Vidéo On nous a dit qu'c'était normal
https://youtu.be/7Hko5tTUmU4

PRESS

https://www.rebellissime.com/endometriose-aynoa-réunit-toutes-les-femmes-du-monde-contre-la-maladie/aynoa/endométriose/endomind/mems/imany/noemie-de-lattre/poème/prières/marianne-bp/we-are-200-million/

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Le bureau de Lilith / lebureaudelilith@gmail.com

LE BUREAU
DE LILITH

Documentary release :

Preview: October 15, 2022 Salle Le Phart Casino Capbreton.
Projections: December 8, 2022 St Joseph Hospital Paris.

Original Soundtrack release: October 14, 2022 - Inouie Distribution.

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Photos : @BeatrizOteroRivera
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@JenniferAsencio @AliciaMigliaro
@IrèneMoukandja @MagdalenaMrozekpytlos
@LeahBattista @KattyClement @SuritaMogan
@KatellVidaman

Layout :
Documentary, trailer, photos : Guillaume Saix / Webmyart
Production file, press release : Anais Vinagre

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Livia

Livia
Le bouton stop pour
vos règles douloureuses

Ziwig

Ziwig

TEXTS ORIGINAL TRACK

We are one out of 10

Aynoa

We are one out of 10, in the world.
Not alone, we claim, our words.
And we fight for our rights,
until we get a cure.
And we pray for the day,
we'll be free.

From Paris to Geneve,
from Tunis to Kenya,
from Québec to London,
I'm giving you my hand.

From Spain to Bueno-Aires,
Poland to USA.
From Gabon to Chili,
I'm giving you my heart.

We are one out of 10, in the world.
We are strong, we claim, our words.
And we talk, and we walk,
until we get a cure.
And we pray for the day,
We'll be healed

From Paris to Geneve,
from Tunis to Kenya,
from Québec to London,
I'm giving you my hand.

From Spain to Bueno-Aires.
Poland to USA.
From Gabon to Chili,
I'm giving you my heart.

On nous a dit qu'c'était normal

Aynoa

Toutes ces années dans le silence,
on a mordu l'bâton,
on a griffé l'plafond,
seules dans nos chambres magmatiques,
le supplice énigmatique.

On nous a dit qu'c'était normal,
qu'c'était comme ça la vie d'une femme,
grandir ainsi c'n'est pas banal,
misogynie médicale.

Parler des règles, c'était tabou.
Et nous, on n'tenait pas debout.
Tais toi, mords l'oreiller,
personne ne doit t'entendre hurler.

Ils ont pensé qu'on était fragiles.
La flèche en plein dans l'mille.
« Exacerbée, tu exagères !
C'est dans ta tête, redescends sur terre »

A chaque fois ressusciter,
devoir sortir des tranchées.
Se repoudrer et remarcher,
comme si rien n's'était passé.

20 ans plus tard, le diagnostic, pas clair:
« C'n'était pas normal, vous êtes malade. »
« Préparez vous à traverser l'désert »
Longue sera « la ballade ».

Le corps dévasté, on a vu défiler, nos vies
volées.
La colère se défouler.
Nos poings levés, nos coeurs dressés ,on a vu
défiler,
nos pas pour une marche décidée.

Les langues se sont déliées.
Les bouches ouvertes pour parler et nos âmes
se lier.
Dire, dire, dire,
Décrire l'invisible.

Dénoncer l'injustice, la minimisation,
la discrimination, l'exclusion.
Sortir de l'ombre, le volcan dans nos ventres.
L'endométriose dans vos vies qui entre.

A jamais, ne plus se taire.
Prévenir la terre entière.
Eduquer nos médecins,
Améliorer les soins,
Chercher un remède,
Trouver un remède.

En te servant du thé

Edgar Sekloka

Elle est pas docile ou fragile.
Le rose des filles c'est du sang.
La guerre contre les mœurs,
ça commence à la naissance.
Classe, pas épilée, l'allure est singulière,
elle fait ce qu'elle veut de son corps.

T'es son fils, pas son père,
exemplaire même quand elle enfante par hasard.
Désert de désirs ou plaisirs en bazar,
c'est elle qui dispose, regarde bien.
Sans elle : par quelle voie accoucherait-on nos lendemains ?
Baisse les yeux endosse son labeur,
quand tu relèveras la tête, ta vue sera meilleure.

L'espoir c'est un risque.
Sous les radars, elle travaille sa liberté,
malgré les larmes volées par le foulard.
La culture souille ses rêves.
En tout cas elle essaie.
Taille mannequin, grosse poitrine et préposée à la vaisselle,
c'est le mythe de la bonne épouse.
Elle a choisi d'être la mauvaise,
elle a renié le confort, elle a choisi d'être à l'aise.

Fière et célibataire aussi,
- sorcière albinos -
Ça la repose des préconçus qui remontent de la fosse.
Ça sent les égouts,
les chaînes rouillées qui pèsent.
Pour s'alléger, elle a la charge mentale qui braise.
Elle brûle son conditionnement
Les fadaises forcées.
Le buste redressé.
La honte de l'avortement.
Assis à sa table, ton messie serait tout p'tit.
T'façon il viendra plus
Y' a plus d'place, elle a tout pris
Les coups, blessures, injures,
les règles, les règles,
de torture à drogue dure.

Les règles, les règles.
Elle en a les cicatrices et chaque matin après le café,
se dit qu'Belle au bois dormant est un conte de méfaits.
L'éloge du non-consenti.
Elle n'aime pas se maquiller,
mais c'est implicite dans la convention collective.

Les bourreaux portent plainte contre celles qu'ils agressent.
Elle a dénoncé son DG, ils ont saccagé son adresse.
En face d'elle, des lobbys, des audits sur le sexe faible,
l'appellent « cougar aigrie sujette au complexe de Phèdre «.
Douleur continue, vieille amie fidèle,
parce qu'on veut d'elle qu'elle soit escort mais pucelle.
Un bordel saint,
pole dance, elle est sur la piste.
Présente mais invisible : m'demande pas si elle existe.
Toute sa vie, elle tue l'aigle de Barbara,
elle combat une égalité d'apparat.

Vu ce qu'elle supporte, vu ce qu'elle brave,
c'est pas étonnant que ma voix soit grave.
Elle fait preuve d'humanité augmentée.
Elle s'oppose à tes discours orientés en te servant du thé.

J'ai un volcan dans mon ventre

Aynoa

J'ai un volcan dans mon ventre,
tu ne le vois pas.
Quand la lave s'écoule, j'deviens esclave,
j'm'écroule.
Mon corps est en fusion, danse la confusion.

J'ai un volcan dans mon ventre,
tu ne l'entends pas.
Les nuées ardentes dévalent les pentes le long
de mes jambes.
Criblée de secousses, j'appelle à la rescousse.

J'ai un volcan dans mon ventre,
tu ne le crois pas.
Quand on me regarde, j'ai l'air complètement
normale.
Personne ne soupçonne l'éruption qui
m'assomme.

J'ai un volcan dans mon ventre,
tu ne l'écoutes pas.
Je suis seule dans ma chambre magmatique,
fusion de roche, je suis en cendres, c'est
explosif.

J'ai un volcan dans mon ventre,
tu ne l'expliques pas,
Fait un effort, relativise,
avec tes phrases, tu m'atomises.

Leurs ventres saignent

Sarah Mathon

Celles qui courent vite
Qui esquivent les coups
Celles qui filent vite
Qui ont le souffle court

Celles qui rient beaucoup
Qui défient le soleil
Celles qui prient beaucoup
Et qui veillent aux merveilles

Leurs ventres saignent

Celles qui jouent le jeu
Qui changent de trottoir
Celles qui disent «je»
Qui chevauchent l'espoir

Celles qui chantent fort
Et qui vivent sans peur
Celles qui parlent fort
Qui terrifient les coeurs

Leurs ventres saignent

Celles qui aiment encore
Qui pardonnent à jamais
Celles qui bercent encore
Et qui lèchent les plaies

Celles qui dansent enfin
Et qui jouissent en pleurant
Celles qui dorment enfin
Et qui vont en rêvant

Leurs ventres saignent

Mon Corps

Aynoa

Tu m'entraînes, dans les bourrasques des tempêtes que tu souffles.
Tu me traînes, et me démasque, le temps s'arrête, et je m'essouffle.

Et moi je t'endors, mon corps.
Le doigt sur la bouche, mon corps.
Et moi je t'endors mon corps, tu ne t'effarouches, mon corps.
Et moi je t'adore encore, je te sers un peu plus fort,
tu vois on s'en sort.

Alors on danse somnolents, on virevolte dans le vent,
on chante, on rit, on rêve, la belle trêve.
Alors on danse ensommeillés, et désinvoltes émerveillés,
on chante, on rit, on rêve, la belle trêve.

Tu me noies, dans les flots gris d'un tsunami que tu soulèves.
Tu m'assoies, endolorie, à pas de loup, tu me réveilles.

Et moi je t'endors, mon corps.
Le doigt sur la bouche, mon corps.
Et moi je t'endors mon corps, tu ne t'effarouches, mon corps.
Et moi je t'adore encore, je te sers un peu plus fort,
tu vois on s'en sort.

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Alors on danse ensommeillés, et désinvoltes émerveillés,
on chante, on rit, on rêve, la belle trêve.

Tu m'inondes, de ta lave incandescente, évanescente.
Ma terre gronde, monte à l'octave, le crescendo à l'indécence.

Prières

Aynoa

J'vais en faire, des prières,
pour qu'tu l'aies ton p'tit bébé.
T'en traverses, des rivières,
faut pas qu't'arrêtes de rêver.

Et tu donnes, qu'est ce que tu donnes,
Ta douleur, elle raisonne.
Mais ne baisse pas les bras,
Tu verras, il viendra à toi.
T'en a versé des larmes ne baisse pas ton arme.
Que les fleurs de ton âme,
gardent leur pétales,
gardent leurs pétales.

J'vais t'en dire, des sourires,
Pour revoir tes yeux briller.
J'les entends tes soupirs,
faut pas qu'tarrêtes de danser.

Et tu donnes, qu'est ce que tu donnes,
Ta douleur, elle raisonne.
Mais ne baisse pas les bras,
Tu verras, il viendra à toi.
T'en a versé des larmes ne baisse pas ton arme.
Que les fleurs de ton âme,
gardent leur pétales,
gardent leurs pétales.