



Better
Awareness &
Support for
Endometriosis



PROFILE

September 2013

Established in March 2013, the Shauna Fuller Clarke's B.A.S.E. Foundation set out to shine a bright light on Endometriosis – a disease often misunderstood and misdiagnosed, not only in Jamaica, but worldwide.

With an estimated 176 million women who have Endometriosis, that is one in every 10 women, it is still remarkable that many people do not know what it is and how deeply it affects those afflicted. Outside of the high medical costs, this disease has a profound emotional and psychological impact on women, which extends from their personal relationships to their workplace.

Background

An Endometriosis sufferer herself, Shauna Fuller Clarke displayed the hallmark symptoms of this disease for 8 years, had a collapsed lung and underwent 3 surgeries before being properly diagnosed. **Today, it takes on average 8-10 years for a woman to be diagnosed with Endometriosis.**

In many countries, there are active associations that inform the public, promote research and provide support to women who have this disease. When Shauna was diagnosed she longed for such support. But with this kind of association lacking in Jamaica, she sought support elsewhere and became very active in the online community where she met many women across the world that have what she has. She was no longer alone. Through support there is strength...and this

is what she received from her online friends.

Her need to connect with her Jamaican "endo-sisters" and lend the invaluable support to them, as she had received, was when the very idea of a foundation was conceived. So Shauna, along with her husband Ricardo Clarke and her mother Sonia Fuller formed the Shauna Fuller Clarke's B.A.S.E. Foundation.

Her Excellency The Most Honourable Lady Allen has recognized the need for this kind of support in Jamaica and is the patron of the foundation.



Her Excellency The Most Honourable
LADY ALLEN



March is Endometriosis Awareness month and yellow is the awareness colour



Co-founders Shauna Fuller Clarke (right), husband Ricardo Clarke (center) and Sonia Fuller (left) at the official launch of the foundation held at Kings House.

Our vision is that a holistic approach is taken in providing the latest and best treatment options to women who suffer from Endometriosis so that prompt diagnosis is given resulting in those afflicted women having a better quality of life.

Our mission is to provide support and information to women who suffer from Endometriosis and promote research in the medical field. We also aim to create better awareness of this disease amongst the general public, women and the medical profession.

For more information, or to make a donation in support of our initiatives, visit us on the web:

www.basejamaica.com
facebook.com/basejamaica
[twitter @basejamaica](https://twitter.com/basejamaica)



Shauna Fuller Clarke's B.A.S.E. Foundation is a registered non-profit organisation.

Registered Office:
80 King Street
Kingston, Jamaica
email: hello@basejamaica.com

The Invisible Disease

What is Endometriosis?

Endometriosis is the name given to the condition where cells like the ones in the lining of the womb (uterus) are found elsewhere in the body.

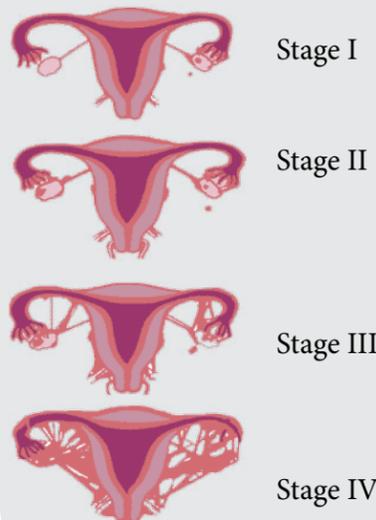
Every month the endometrium – uterine lining – builds up with blood cells and other chemicals to prepare for pregnancy. When pregnancy doesn't occur then the endometrium sheds this blood and women have a "period".

A similar reaction takes place in these stray cells (endometrial implants) that have found their way to the pelvic area, and more uncommonly in other areas of the body such as the skin, eyes, spine, lungs and the brain.

They react to the hormones, break down and bleed, but the blood and tissue shed have no way of leaving the body.

This causes internal bleeding, breakdown of the blood and tissue from these sites, and inflammation – which can cause pain, infertility, scar tissue formation, adhesions, and bowel problems.

Stages of Endometriosis



Possible Signs of Endometriosis

- Intermittent and/or chronic pelvic pain
- Bowel or urinary disorders
- Gastrointestinal and urinary tract distress
- Painful menstruation
- Autoimmune-related disorders
- Rectal pain
- Painful intercourse
- Severe cramps lasting more than 1-2 days
- Infertility and pregnancy loss

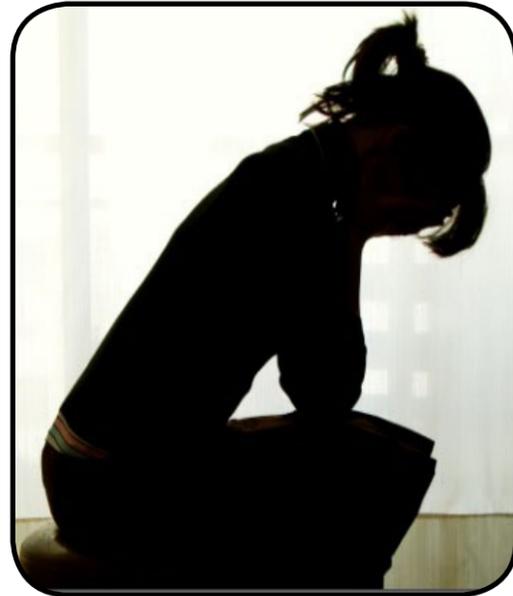
Treatment Options

Currently, there is no known cure for endometriosis.

Different treatments available aim to reduce the severity of symptoms and improve the quality of life for a woman living with the condition.

They can help by relieving pain symptoms; shrinking or slowing endometriosis growth; preserving or restoring fertility; or preventing/delaying the recurrence of the disease.

1 in 10 girls and women have endometriosis - 176 million in the 15 to 49 age group worldwide.
That's BIGGER than the combined numbers with breast cancer, prostate cancer, diabetes (type I and type II) and aids!



“Imagine a bucket full of balloons. Then imagine you poured glue on top of that. That is what the organs would look like of a woman with Stage IV Endometriosis.”

Dr. Loxley Christie
Gynaecologist and Consultant at Hugh Wynter Fertility Management Unit, UHWI

Courtesy Calls & Presentations



Ricardo, Shauna, US Ambassador Pamela Bridgewater and Sonia strike a pose at the end of discussions.



Shauna officially pinning Ambassador Bridgewater at the US Embassy.



Shauna and the Hon. Lisa Hanna in deep discussions on the impact of endometriosis



The Hon. Lisa Hanna, Minister of Youth and Culture being pinned by Shauna and Sonia.



Shauna, Her Excellency the Most Honourable Lady Allen and Digicel's HR Director Andrea Dempster at Digicel's inaugural Wellness Fair.



Renowned Dr. Wynter & husband Professor Hugh Wynter take a moment to pose with Shauna after making presentation at Lay Magistrates & JP Meeting for St. Andrew.

The Official Launch at King's House



Guests of the launch included front row left to right: Their Excellencies the Most Honourable Sir Patrick Allen and Lady Allen, Lady Hall, Minister of Health the Hon. Fenton Ferguson, Minister of Youth and Culture the Hon. Lisa Hanna



Custos of Kingston Hon. Steadman Fuller greets Lady Hall



Her Excellency the Most Honourable Lady Allen bringing remarks as the Patron of the foundation



Shauna speaking to guests about her personal experience and explaining why the foundation is important



Shauna and Ricardo have light hearted chat with US Embassy official.



Invited guests listening attentively to presentations



Shauna greets guests at the end of the launch



Guest speaker Professor Joseph Frederick and Chief Justice Zaila McCalla in engaging discussions



L to R: Dr. Loxley Christie, Sonia, Shauna, Her Excellency the Most Honourable Lady Allen and Mario Evon enjoy a light moment after the launch



Their Excellencies the Most Honourable Sir Patrick Allen and Lady Allen congratulate Shauna on the launch of the foundation

Other Appearances

- TVJ's Smile Jamaica "10 Minutes To Your Health"
- The Susan Show March 21, 2013
- Morning programme on Nationwide News Network on March 18-19
- Articles in Jamaica Observer (March 25th) and Jamaica Gleaner (March 22nd)
- "Big People Business" on Hot 102, April 2013
- Special presentation at US Embassy for Health and Wellness Week, July 8

SUPPORT GROUP MEETINGS

In May 2013, we launched monthly support group meetings in Kingston which provide a secure and confidential space for girls and women to share and learn from each other.

Special speakers are also invited to attend the support group meetings on occasion to assist in lending support – these speakers include mental health professionals who give counsel to those suffering from depression and other related issues.

There is hope...

Although a “young” foundation, we have already started to see the effects of increased awareness and support:

- ✓ Women have started to doubt that the chronic pain they have been feeling for so many years is “normal”
- ✓ Women are visiting their doctors and are being treated (some have already had surgeries)
- ✓ Those who have fertility issues now know the cause of their inability to conceive

✓ Women are now getting the support that they need to cope with this disease and

✓ An H.R. manager in particular now understands that her employee was not “faking” the pain she felt at work, and is now working with the employee so that she can cope more productively at work.

But there is still so much work to be done. Many girls and women are still misdiagnosed or not diagnosed at all...and this is unacceptable given the debilitating nature of this disease.



Women see an average of 7 health care professionals before they are referred to a specialist and treatment is commenced.

Our Objectives

In order to fulfill the B.A.S.E. movement, there are four main objectives:

1. Awareness

Host special events that promote awareness amongst women, the general public and the medical profession

2. Support

Set up network(s) and train volunteers that can provide support to women with Endometriosis.

3. Information

Provide information through pamphlets, our website and social media.

4. Research

Promote research into Endometriosis in Jamaica.

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Sometimes, reaching out and taking someone's hand is the beginning of a journey. At other times, it is allowing another to take yours.

Vera Nazarian

Projects: Help us help Jamaican girls and women who have endometriosis

1. B.A.S.E. @ School

Many young girls exhibit hallmark symptoms from they are in high school, and early detection and intervention are critical in assisting them in minimizing an escalation of the disease.

Not only is productive learning time affected by this disease, but quite often the debilitating pain experienced by young girls is belittled or is categorized as “an excuse” for not attending school.

Therefore, an educational campaign specifically targeting schools, including school nurses and the parents of these girls is important so that:

- a. Steps can be taken to get them to a doctor once symptoms are experienced (through proposed pre-screening initiative) and
- b. Meaningful discussions can be held on how to facilitate students who are truly affected by this disease.



An Immaculate Conception High student engages Shauna and Paula Fletcher

2. B.A.S.E. @ Work

Employees are the most valuable asset in any organisation and their welfare has a direct impact on the success of the organisation. But, many employers are unaware of this disease and its debilitating nature, which has not only resulted in loss of productivity but has also resulted in depression and other psychological issues affecting employees who suffer from this disease.

B.A.S.E. at The Workplace aims to do the following:

- a. Equip members of the JEF, HRMAJ and employers with information on the disease, treatment options, ways to access help and strategies to cope more productively in the workplace.
- b. Integrate into current wellness programmes, or introduce a wellness programme to help employees and the organization make better informed decisions regarding health choices so that they benefit from improved productivity and improved staff morale with less absenteeism.

3. B.A.S.E. @ The Doctor

Our primary target is to provide information about this chronic pelvic pain disease to young girls and women - whether they exhibit symptoms or not.

B.A.S.E. intends to make informational flyers available island-wide in the offices of general practitioners and gynaecologists. These flyers will highlight the possible symptoms of Endometriosis, what it is and how they can be a part of a support group meeting.

4. Registry of Gynaecologists

Currently, there is no database of gynaecologists in Jamaica, and even if a telephone directory is used, many doctors do not include their specialization in the listing. This poses a problem for those young girls and women who seek the necessary healthcare to manage this disease.

B.A.S.E. will create a database that includes the contact details of all practicing gynaecologists in Jamaica. Of note, not all practicing gynaecologists are qualified to do operative laparoscopies, which is a critical aspect in treating women with Endometriosis. This will also be included in the database. A registry of this kind will significantly help us in assisting women in identifying gynaecologists located close to their home, school or workplace so that they can get prompt healthcare.

5. Workshops

Due to the high level of misdiagnosis, we will host a series of workshops, each targeting a specific sector of the medical fraternity and alternative therapy professionals: including but not limited to medical students, student nurses, and general practitioners.

Reputable individuals or organisations (based locally or overseas) will be invited to make special presentations on the symptoms, research and the latest treatment options for Endometriosis. This, we believe, will not only expose a greater number of health care professionals to this disease, but it will also encourage necessary discussions of employing a holistic approach when treating Endometriosis.

**Important
DATE!**

Million Woman March for Endometriosis | 13.03.2014

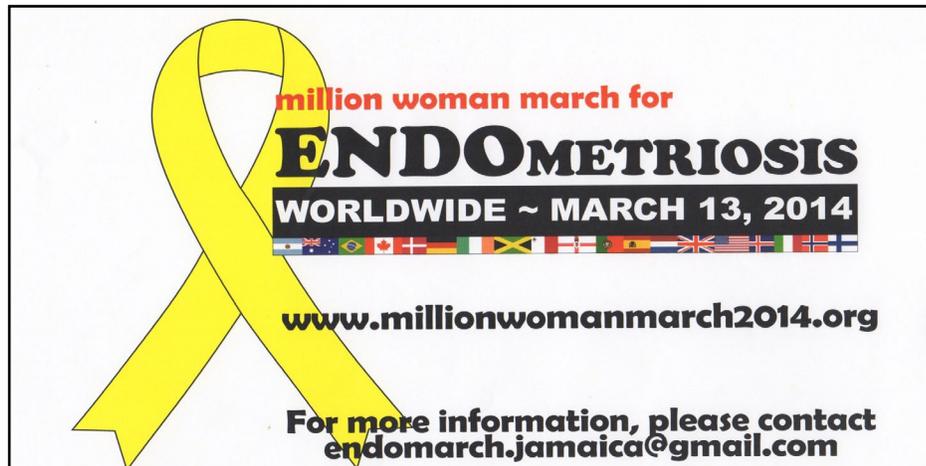
We invite you to join the Million Woman March for Endometriosis®, an internationally-coordinated awareness campaign that will occur worldwide in dozens of international capitals, including Amsterdam, Berlin, Buenos Aires, Copenhagen, Dublin, Helsinki, Lisbon, London, Madrid, Rome, Stockholm, and Washington, D.C., just to name a few.

With an estimated 176 million women and girls throughout the world still living lives awash in anguish because of this devastating disorder, we believe that an internationally coordinated campaign is absolutely necessary to effect the changes that are needed to overturn the status quo.

This unprecedented worldwide peaceful demonstration to raise awareness about endometriosis, adenomyosis, fibroids and other related pelvic pain disorders in women, is scheduled for **March 13, 2014**.

We are pleased to share that Jamaica will be participating in this global event, and that our very own Shauna Fuller Clarke is the Country Captain!

We are also very proud, that due to our early commitment to be a part of this momentous initiative, our Jamaican flag was included in the official logo of Million Woman March 😊



Our nation's medical and nursing schools need to do a better job of educating future physicians and nurses. Therefore, we will be demanding change at these public and private institutions. We will also be asking medical researchers to

Goals of Million Woman March

In addition to the broad goals of simply raising awareness, we will be seeking change in the following **four (4) sectors**:

1) Government-funded Health Organizations

It's crucial to work with governmental institutions, for example – Ministry of Health, National Health Fund – to effect the broad changes that are needed to overturn the status quo. Regarding the NHF, for example, we believe that the Endometriosis should be included in the list of chronic diseases.

2) Ministries of Health & Education, Health Screening in Schools

We will be requesting that the Ministries of Health & Education help us launch nationwide health screening in schools to screen for endometriosis and other chronic pelvic pain conditions that afflict girls.

3) Medical and Nursing School Educational Institutes

help us find cures and develop noninvasive tests for disorders that have been devastating millions of lives for thousands of years.

4) Media coverage, public education campaigns

And, finally, we are holding this worldwide mass demonstration to raise awareness in the media and in our local communities. Media coverage about endometriosis, for example, is woefully inadequate given that millions of women and girls have had their lives torn apart by one of the most painful and crippling disorders ever catalogued in the history of humankind.

JOIN US as we stand together and shine a bright light on Endometriosis and other chronic pelvic disorders...let us turn out in historical numbers and show the world that yes, **“we likkle but we tallawah!”**

To volunteer or attend the event, or for more information, please contact us at

endomarch.jamaica@gmail.com

or register at

www.basejamaica.com/march4endo



About 30 to 40 percent of women with endometriosis are infertile, making it one of the top three causes for female infertility.