



4/12/2023

# Endometriosis Awareness Month 2023

Patient Academy for Innovation and Research (PAIR)



## Women with wings

**Women with Wings** is an initiative of “**The Patient Academy for Innovation and Research**” dedicated to women's health providing a safe and supportive space for women to come together to share their stories, discuss their experiences, and find help and understanding.

We strive to disseminate accurate information, education, and support to those living with the conditions which are under-highlighted.

**Endometriosis Awareness Month** is celebrated annually in March to increase awareness about the chronic and painful condition affecting millions of women around the world. It is a painful disorder in which tissue like the tissue that normally lines the inside the uterus — the endometrium — grows outside of the uterine cavity, causing intractable pelvic pain, dysmenorrhea, dyspareunia, and infertility.

**It is estimated that up to 80% of women with dysmenorrhea and up to 40% of infertile women have endometriosis.**

Despite being a common condition, affecting approximately 10% of women of reproductive age, endometriosis is still underdiagnosed and often misunderstood.

This year, **Women with Wings** with support from “**Bayer Pharmaceuticals India**” and hygiene Partner, “**Paree**” planned to celebrate the lives of women with endometriosis by commemorating events in five cities and a monthlong social media campaign to garner interest and raise awareness around the condition. The month of March 2023, celebrated around the world as Endometriosis awareness month had the following activities-

1. Endorun in five cities
2. Panel discussion on Endometriosis and infertility
3. Social media campaign

### **Outcomes from the event-**

#### **1. Increased visibility of the Women with wings groups highlighting the endometriosis cause-**

- 1.1. Endometriosis Awareness Month encouraged people to become aware of the disease and significantly understood the need for greater support and understanding for those affected by it.
- 1.2. As a result, there has been a significant increase in the number of women joining the advocacy group, seeking medical help for their symptoms, which can often be misdiagnosed or overlooked.

#### **2. Improved education about endometriosis-**

- 2.1. By raising awareness, advocating for people living with endometriosis, and breaking down stigma, Women with Wings has helped to improve the lives of millions of women living with this condition.
- 2.2. Through these campaigns and initiatives, it has helped to educate people about the symptoms, diagnosis, and treatment options available for endometriosis.

#### **3. Increased support for those living with endometriosis-**

- 3.1. EndoRun as an event, created a difference in the lives of women fighting with endometriosis addressed social and cultural barriers in getting a timely diagnosis, seeking treatment, stigma of normalization of periods pain and lack of access to reproductive health services.



- 3.2. The panel discussion emphasized a patient-centered, multi-disciplinary treatment approach considering the physical and psychological needs of patients.

**4. Strengthening the group with increased membership-**

- 4.1. Women with wings has recorded increased membership over each platform by patients, caregivers, healthcare professionals (HCPs), researchers, patient advocates but not limited to gender spectrum. We have successfully amplified the message of inclusive participation throughout the campaigns and public events.
- 4.2. There is a diversity of perspectives and experiences that new members have brought to the group. This has helped to broaden the group's understanding of the issue at hand and provide new ideas for creating awareness strengthening the group's impact and effectiveness in achieving its goals.





## 1. #EndoRun- A step towards Endometriosis Awareness

March is designated as Endometriosis awareness month, **Women with wings- Endometriosis Support group** organized Pan India events in Delhi, brought together 200 people including endo warriors, their families, healthcare providers, researchers, and advocates, to march/walk for a shared cause.

### Delhi:

The Delhi edition of EndoRun was organized in local partnership with **Milestone, a non-profit organization**, working on empowering and rehabilitation of women, children and youth, creating awareness among community members about health and maternal health issues.



The chief guests for the event were **Dr. Madhu Goel**, Director, Fortis La Femme, **Ms. Suman**, “Oscar Woman” –Period End of Sentence, along with **Mr. Deepak Chopra**, Business Head Women’s health, Bayer Zydus Pharmaceuticals, India came together to raise awareness for endometriosis.

### Pune Edition:

The EndoRun started from North Gate, Phoenix City Mall and was organized by local partners and supporters, an endo warrior and patient advocate, **Dr. Shilpa Rao**, her core team member, Dr. Vinita Sharma, and with the support of the entire team of **Mr. Sathyanatarajan**, **Swachh Partner**, **Adar Poonawalla- Clean City Initiative** and **Richa Mistry**, Zumba instructor, who engaged the audience for warm up.

The event was graced by **Ms. Sonali Kakde**, Mrs. India Empress of the Nation 2021 and **Mr. Surendra Babusaheb Pathare**, Founder and President, Surendra Pathare Foundation, along with the endo warriors and patient advocates who rendered the support for endometriosis community.





### Hyderabad:



The EndoRun in Hyderabad was organized in local partnership with **Holistic Nutrition works** and support of **Dr. Suresh Kumar Vunnamatla**. The chief guests for the event **Dr. Rooma Sinha**, Senior Consultant Gynecologist, Laparoscopic & Robotic Surgeon, Apollo Health City, Hyderabad.

**Dr. Meher Lakshi DM**, Associate professor, NIMS and **Ms. Haritha Shyam**, HOD, Department of Nutrition, Apollo Hospital spoke about the need for greater awareness about endometriosis and encouraged participants to make a



difference in the lives of those who are affected by this condition. The event was a huge success, with participants running for a cause and raising awareness for endometriosis research.

### Kolkata:



The EndoRun in Kolkata was organized in partnership with Anahat for Change Foundation, an organization that works in the space of women empowerment through skill building and livelihood generation with sustainability at its core and team “Sarsuna College”.

The expert and chief guest, **Dr. Basab Mukherjee** created awareness on awareness amongst college students with the right and accurate information. The chief guest, “**Subhankar Tripathi**” for the session spoke about the need for greater awareness about endometriosis and the importance of supporting women who suffer from this condition.



- Through these events, we provided support and solidarity, to encourage people to join in the fight to support those suffering from endometriosis with a raft of virtual events and activities, including the **#EndoRun**.
- In addition to advocacy and awareness-raising, through these events Women with wings offered free resources, support group information, and educational materials to help those affected by endometriosis better manage their symptoms and improve their quality of life.

## 2. Launch of Endometriosis Patient Stories

A coffee table book was launched by TEAM PAIR and BAYER. It has narratives of endometriosis patients, their stories of grit and courage and survivorship. Their fight to overcome the condition, challenges faced and each one unique perspective on how they managed to overcome their challenges in each city to showcase and amplify the brave stories of women fighting with this debilitating condition affecting as much as 175 million women worldwide with a message, “**You are not alone in this journey**”.





### 3. Social media campaign for Endometriosis

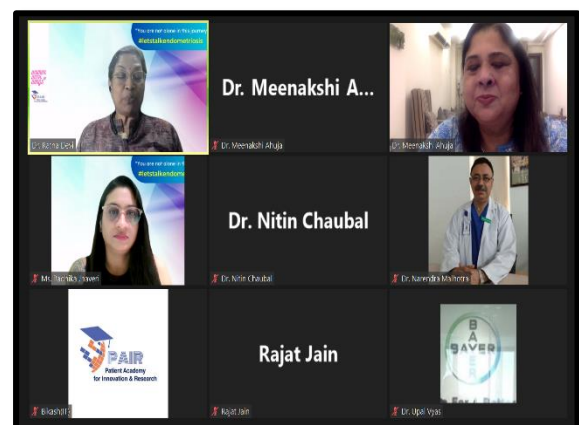
Women with wings also used social media platforms to encourage endometriosis patients to share their journeys, educate others about endometriosis, and advocate for better care and treatment options showing solidarity to the endo community.



These posts had more than 70-86% engagements on each social media platforms including LinkedIn, Instagram and Facebook.

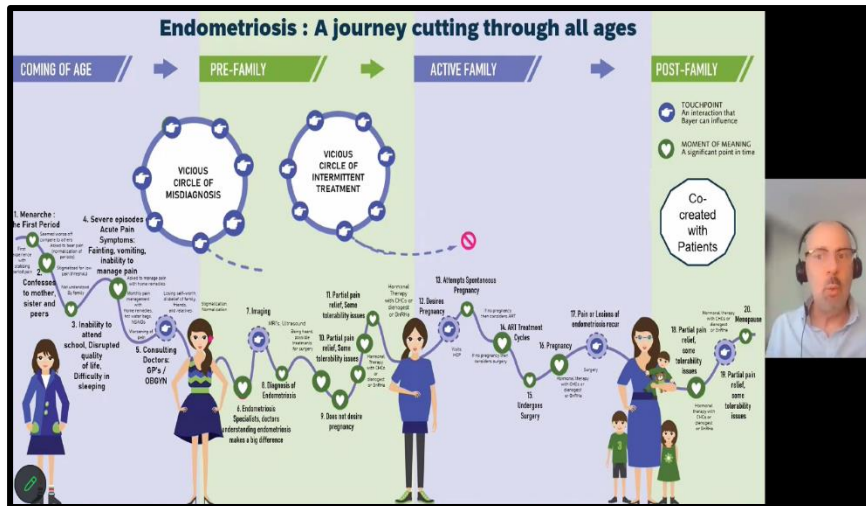
### 4. Endometriosis Awareness Month Panel Discussion

Endometriosis is a complex chronic condition often underdiagnosed or misdiagnosed, which can lead to delayed treatment and increased suffering for women with the condition. It is pivotal to raise awareness around this disease. This was the focus of the Panel Discussion, on **31<sup>st</sup> March**, with expert speakers, **Dr. Narendra Mahotra, Dr. Nitin Chaubal, Dr. Meenakshi Ahuja, Mr. Peter Said and Ms. Radhika Jhaveri** providing clarity on the disease's causes, prevention, diagnosis, management, and treatment for women who are still undiagnosed.



The session highlighted-





- Need for increased awareness, education, and access to specialized care and diagnostic tools to improve outcomes for women with endometriosis in the country.
- Need for improved access to diagnostic services and treatments, as well as the need for greater financial and emotional support

for those struggling with endometriosis.

- Listening to the patient and understand their individual needs in order to provide the best possible care. Endometriosis is not just a physical issue, but also a mental and emotional one.

The discussion had 40+ participants and 60+ registrations from different parts of the world and the outcomes were-

- The patients gained better understanding of Endometriosis.
- Addressed social and cultural barriers to seeking treatment, such as stigma and lack of access to reproductive health services.
- Emphasized on patient-centered, multi-disciplinary treatment approach considering the physical and psychological needs of patients.
- The session was liked and supported by existing patients even on social media channels shared, supported widely by people, groups, and organisations.

YouTube Link- <https://youtu.be/tl-kRN4p55U>

## 5. Patient Outreach



- The Women with wings group has been joined by patients from different parts of the world.
- 120 women are part of Whatsapp Group.
- Women with wings has 750 followers from Facebook, 936 followers from LinkedIn, 235 followers from Instagram, and 178 followers from Twitter
- 15 patient advocates worldwide.
- Created awareness about Endometriosis.

- Provided access to correct and updated information on issues related to endometriosis.



## Mumbai -

The Mumbai edition of EndoRun was organized in local partnership with **R.D. & S.H. National College and S.W.A. Science College.**



The **chief guest** for the event was **Dr. Hemant Kanujiya**. He is an **EXPERT MEDICAL CONSULTANT** in **GYNECOLOGICAL ENDOSCOPIC SURGERY** at the **COOPER MEDICAL COLLEGE, JUHU, MUMBAI**. Dr Hemant raised awareness among students through **“ENIGMA OF ENDOMETRIOSIS”** and provide them with accurate information about endometriosis, the silent disease.





**Dr. Ashlesha Tawde Kelkar (Guest speaker)** Retd. Army Medical Corps. During her speaker session, Dr Ashlesha talked to student about “Endometriosis: Risk Response and Raksha.”



**Dr. Manoj Saxena** is the Managing Director at Bayer. He informed the students about the endometriosis disease and advised them to have complete and accurate information about this condition.

**Dr. Chinu Kwatra (Celebrity Guest)** said that the term "endometriosis" is completely new to them. And to fight against this silent disease, men should also provide their full support alongside women.



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In this event, we also organised a Zumba session for the students. Through this session, we conveyed the importance of fitness to the participants/students.

