

The Endometriosis Foundation of America's
Advocacy Toolkit



Table of Contents

What is Advocacy?.....	3
History of Our Advocacy Work.....	4
Tell Your Story & Make An Impact.....	6
Tips to Consider.....	8
Using Social Media The EndoFound Way.....	9
Email Template.....	10
Tools to Use.....	11
Patient Story.....	12
Fact Sheet & Common Qs About Endometriosis.....	15
Get Involved.....	19

About EndoFound

The Endometriosis Foundation of America (EndoFound) is the nation's leading nonprofit organization dedicated to increasing disease awareness and recognition, advancing landmark endometriosis research, and providing critical education on endometriosis. Founded in 2009 by Dr. Tamer Seckin and Padma Lakshmi, EndoFound works to improve early diagnosis, treatment outcomes, and quality of life for those affected by the disease.

Engaged in a robust campaign to inform both the medical community and the public, EndoFound places particular emphasis on the critical importance of early diagnosis and effective intervention while simultaneously providing education to the next generation of medical professionals and their patients.

What Is Advocacy?

Advocacy is taking action to influence policy—in this case, health education on endometriosis and other menstrual disorders. Our advocacy team is committed to speaking up about the policy needs of the endometriosis community, and our advocacy campaign focuses on the importance and need of including endometriosis in the health class curriculum that state education departments create and schools implement. An EndoFound advocate engages with state elected officials to help them understand what endometriosis is, the importance in recognizing the signs and symptoms, as well as information concerning proper treatment. This work plays a critical role in helping to secure federal funding for endometriosis research and education.

As an organization, our mission is to encourage education to increase disease recognition and provide advocacy for early diagnosis and effective intervention. The most important tool you possess is your story. Whether you're a patient, a partner, a family member, employer or friend, everyone's experience with endometriosis is different, valid, and needs to be heard. Despite the recent increase in public awareness of endometriosis, many still do not know what the disease is, or how debilitating its effects are on patients. We've included a story of a patient that portrays just how difficult living with endometriosis can be—a story to share with others, in addition to your own.

Being heard will make a difference in the lives of people who experience endometriosis or are caregivers to those with endometriosis.

We've included resources that will guide you through every step of advocacy with EndoFound, regardless of whether you've lobbied for a cause before. Together we can drive awareness and build lasting change.

Let's be heard!



History of Our Advocacy

Work

EndoFound is the voice on Capitol Hill, in statehouses around the country, and with federal agencies for those who have endometriosis.



A key part of this effort is our **UpEndo Coalition**, which brings together thousands of members nationwide. This growing community unites advocates, patients, and families to amplify education, share resources, and ensure endometriosis is recognized as a public health priority. Together, the coalition demonstrates the power of collaboration in driving awareness and building lasting change.

At the national level, our team raises awareness through educational briefings, meeting and educating elected officials about the disease, public events, and coalition building.

Milestones

2019

EndoFound's two-year advocacy initiative with New York State resulted in the **first law** in the United States to make **materials on menstrual health and endometriosis** available to school districts and medical practitioners statewide.

2020

EndoFound and the **bipartisan Congressional Endometriosis Caucus** worked to raise awareness of endometriosis, resulting in a **historic doubling of funding for endometriosis research** at the National Institute of Health (NIH).

2022

EndoFound launched the **UpEndo Coalition** to educate the public and Congress about the health implications of endometriosis and ensure policymakers are advancing research funding and other policy priorities.

2022

The caucus introduced the **bipartisan Endometriosis CARE (Coverage, Awareness, Research, and Education) Act**, led by Representatives Lauren Underwood, Nikema Williams, Jenniffer González-Colón, and Alma Adams. The legislation called for **significant investments in endometriosis research** and public awareness campaigns and is a critical step toward the future patients deserve.

Tell Your Story & Make

an Impact

You have a story to tell—one that you know others need to hear; a story that is shared by many who live with endometriosis. Maybe you want your story to make an impact, or you want to ensure that other people will not experience the pain that you did with this disease.

Where do you begin?

Consider advocacy, one of the most effective ways to bring individual and community needs to a larger institution. Educating the elected officials that represent your needs and the needs of those you love, in either your state capital or in Washington, D.C., is the first step towards making lasting policy change concerning endometriosis education and awareness.

Remember: Elected officials want to know what their constituents need, and it's important for them to understand the needs of their district residents in order to protect the interests of their constituents, their supporters, and those that didn't support them.

You will need to determine which members of your state or federal delegation you anticipate meeting with in both houses of the legislature. The elected officials you want to meet with are not those that are only in your local area. Not all the legislative members of the Health and Education Committee will be local to you, so we recommend determining when and which location is best for you to travel to.

You will also want to do some initial research to determine which elected officials are assigned to the education and the health committee. Create a list of email addresses and telephone numbers, and be sure to include office locations. Learn when your state legislature is in session, which is the time of year legislators from around the state conduct the People's work in the state legislature.

It is important to create a rapport with the staffers in each office because they will be the people who will advise your representatives about your story and why it's important. Reach out to the education and health committee members however you are most comfortable, whether that is email or telephone call. Be prepared to tell the staff person (very briefly) the reason you are requesting a meeting.

Once you have an appointment you can tell your story in more detail. Telling your story puts a face to the issue that endometriosis needs more attention. Specifically, education about endometriosis across schools must be mandated in order to properly understand the disease and ensure that patients in that very community are able to seek timely detection and receive appropriate treatment.

Think of this meeting as your time for myth busting.

You can go one of three paths...



**Make a
phone call**



**Send an
email**



**Meet in
person**

Tips to Consider

Regardless of which approach you take the following steps will help facilitate sharing your story:

1 Plan ahead

2 Identify yourself

3 Schedule an appointment

4 Understand that you may be meeting the elected official's staff member(s)

5 Stay on topic and remain focused

- Determine what you'll say and keep your points clear and focused.

6 Tell your story

- Use our patient story included below if you don't have your own personal story to share.

7 Be courteous and patient

- Unforeseen circumstances happen during lobby days and the elected official will remember the patience you had. A positive way to be remembered.

8 Leave educational materials and information for the elected officials to share with their colleagues.

- Tools to Use section

9 Thank-you email and follow-up

- This is the time to summarize the talking points during your meeting and let them know you appreciated the time they took to discuss the importance of early detection and effective treatment of endometriosis.

10 Ask for a written reply

Using Social Media the

Endo Found Way

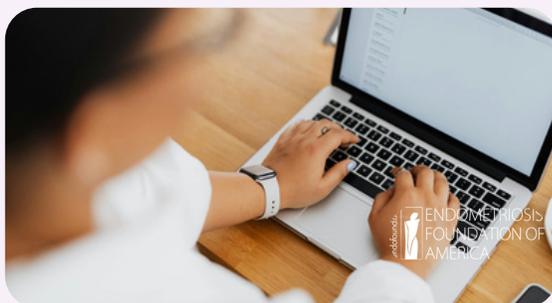
Social media is as powerful of a tool as any to get the word out about endometriosis, its signs and symptoms, how to get properly diagnosed, and best treatment options.

Don't be shy to share your story using your platform. It can make a world of a difference and quite literally change the course of both a dear friend's life as well as a complete stranger.

We recommend tagging @endofound as well as any other accounts from which a repost would garner even more visibility. Hashtags increase engagement as well, including but not limited to: #endometriosis, #endometriosisawareness, #endowarrior, #endo, #endometriosiswarrior, #endometriosisupport, #chronicillness, #chronicpain, #invisibleillness, #endosisters, #endostrong, #endometriosiscommunity, #livingwithendo, #endometriosisjourney.

Using Traditional Media: Letters to the Editor, Op-eds & Emails

Write to your local paper, and your community, however big or small! We encourage you to introduce yourself and what you hope to share, and to focus on your story. A personal ask can move mountains. Be sure to personalize the email draft below that you can send to your community.



Email Template:

Dear [Editor/Community Member],

My name is [Your Name], and I'm writing today to share something deeply personal in the hope that it will help spark awareness, understanding, and change.

I live with endometriosis, a chronic and often misunderstood disease that affects millions of people worldwide. For me, endometriosis has meant [briefly describe your experience—for example: years of pain, missed work or school, delayed diagnosis, impacts on mental health, fertility, or daily life]. Like so many others, I spent far too long being told that my pain was “normal,” only to later learn that it was not.

Endometriosis is more than “bad periods.” It is a whole-body disease that can cause debilitating pain, fatigue, and infertility. Despite how common it is, diagnosis often takes many years, and many people suffer in silence due to stigma, lack of education, and limited access to specialized care.

I'm sharing my story because awareness matters. When we talk openly about endometriosis and other chronic illnesses, we make it easier for people to recognize symptoms, seek care earlier, and feel less alone. We also help push for better research, improved medical education, and policies that support those living with chronic pain.

My personal ask is simple: please help amplify this message. Whether by sharing this story, starting conversations, or learning more about endometriosis, your support can make a meaningful difference. No one should have to endure years of pain without being heard or believed.

Thank you for taking the time to read this and for being part of a community that cares. Together, we can move awareness forward and create space for understanding, compassion, and change.

With gratitude,

[Your Name]

Tools to use

* State website of elected officials (differs per state) but can be accessed through this link: <https://www.usa.gov/elected-officials>

* Federal website of elected officials:

- Locating your Representative:

<https://www.house.gov/representatives/find-your-representative>

- Locating your Congressman or Congresswoman:

<https://www.govtrack.us/congress/members>

* [The New York State legislation](#) that was enacted by the legislature and signed into law. This will help you understand what you're advocating for and will provide a template for the elected officials you meet.

* Patient Story

* Frequently Asked Questions

Patient Story

A vignette

Meet Maya. Maya loves to play basketball, listen to Taylor Swift, and hang out with her friends. Maya started experiencing symptoms at age 13, when she got her first period. She noticed that her period was heavy, but she wasn't sure how much blood she was supposed to see, so she didn't make a big deal of it. She also had really bad cramps before and during her period that neither Tylenol nor Advil eased. She was embarrassed to ask her friends or parents about how a period is supposed to feel, so she stayed quiet, even when the pain became so difficult to bear that she began missing school and activities with friends.

Maya doesn't know it yet, but she has a disease called endometriosis. Endometriosis occurs when endometrium-like tissue is present outside the uterine cavity where it does not belong. Most people have not heard of endometriosis, but it affects 1 in 10 women/individuals born with female reproductive organs. Those who have a close female relative like a mom, an aunt or sister with endometriosis are 5-7 times more likely to have endometriosis themselves because it is a hereditary condition, passed from one generation to the next.

When Maya started high school, things got worse. In addition to “killer cramps,” pain that is well beyond a nuisance or inconvenience, and heavy bleeding, she was always tired, her back hurt and she had pain when going to the bathroom. Sometimes her pain was there even when she wasn't on her period. She missed basketball tryouts because of her symptoms. During her sophomore and junior years, she began to notice digestive issues: vomiting and diarrhea. Due to her illness, her grades began to suffer; she was missing out on so much, and she began to grow apart from her friends. Maya was beginning to lose interest in her favorite things, and this began to give her an uneasy feeling and made her feel sad and isolated. Maya began feeling depressed and anxious.

Patient Story

Cont.

Maya knew she had to do something, so she made an appointment with her family doctor. She explained how she was feeling, and the doctor said many different things could be causing her symptoms. Maya described the stomach pain she was experiencing, and her problems with going to the bathroom. As a result, the doctor diagnosed Maya with Irritable Bowel Syndrome (IBS). Together, they decided on a treatment plan.

Unfortunately, Maya like many young girls, was misdiagnosed and the treatment plan did not seem to help. Her pain continued and she continued to miss out on many fun and important activities.

During her senior year, Maya learned about endometriosis during health class, and was told she should visit a gynecologist, a doctor who deals specifically with the female reproductive system (ovaries, fallopian tubes, uterus, cervix, vagina, and vulva). Whether you have all, some, or none of the symptoms of endometriosis before or during your period it is important to make an appointment and be seen by a gynecologist. Maya was lucky—this gynecologist had been educated about endometriosis and thought Maya might have the disease.

It is important to note that not everyone has the same symptoms, and it can take on average between 7-10 years for a correct diagnosis. Maya's relatively earlier diagnosis than most patients was due, in large part, to proper education about endometriosis—both on the part of her health class teacher as well as her gynecologist. This is why early education for the disease is so critical.

Vignette History & Rationale

Maya's story is unfortunately all too common, but she was fortunate to have learned about endometriosis in her health class. There is still not enough awareness about the disease, which means patients may see many different kinds of doctors before realizing they need to see a gynecologist. As a result, many are misdiagnosed with other diseases, just as Maya was first misdiagnosed with IBS. Misdiagnosis happens so often it takes an average of 7-10 years for a person to be accurately diagnosed with endometriosis, when it should be identified as soon as symptoms begin. If you recognize the signs of endometriosis and know what type of doctor to see, you have the best chance for a healthy future.

So, what can you do? You have the power to raise awareness and educate your friends and family about endometriosis.

Discuss endometriosis with them. Send them a text, or post to social media. You can help spread the word about the disease and become an advocate by using your voice. If you tell everyone you know, and they tell everyone they know, think of how many people you can help realize that the pain they are feeling is not normal. You have the power to change the lives of other people who would otherwise suffer even more due to delayed treatment.



Fact Sheet & Common FAQs about Endometriosis

What is endometriosis?

- Endometriosis is a complex systemic disease associated with tissue similar to the endometrial lining of the uterus growing outside the uterus. The disease is not simply a “menstruation disease,” as it can affect the whole body.
- The disease is characterized by lesions called implants, nodules, or endometriomas that can respond to monthly fluctuations of hormones during the menstrual cycle. During this cycle, estrogen can cause this out-of-place tissue to grow, often causing severe pain.
- As endometriosis grows, it causes inflammation, which can lead to adhesions, scarring, internal bleeding, bowel or urinary dysfunction, constipation, painful intercourse, or infertility. The physical pain can be severe, which can lead to psychological distress.
- The disease can take on average between 7-10 years for a correct diagnosis.
- Endometriosis is one of the leading causes of infertility.

How many people have endometriosis?

- Endometriosis affects an estimated 200 million women/individuals born with female reproductive organs worldwide and in the United States, approximately one in 10 girls and women of reproductive age, which is roughly from ages 12 to 49 in women/individuals born with female reproductive organs.

Fact Sheet & Common FAQs about Endometriosis

What are the most common symptoms of endometriosis?

Signs and symptoms are not the same for everyone and can include some or all of the following:

- Killer cramps
- Long or heavy periods
- Lower back pain
- Trouble getting or staying pregnant
- Vomiting
- Diarrhea
- Nausea
- Pain when going to the bathroom
- Leg pain
- Fatigue
- Painful sex

Why do so few people know about endometriosis?

Because of the lack of education about endometriosis, pain or other symptoms are often dismissed as “part of being a woman” or misdiagnosed. This often causes a delay of a decade or more in receiving the proper diagnosis of endometriosis.

Is there a "cure" for endometriosis?

There is no cure for endometriosis, but there are many treatment and management options to greatly improve patients' quality of life.

Fact Sheet & Common FAQs about Endometriosis

What impact does endometriosis have on a patient's life?

- Endometriosis often impacts all aspects of someone's life.
- It can interfere with attending school and participating in athletics or other extracurricular activities.
- It can alter career choices or even force a patient to give up a career.
- It can affect finances as one struggles to get a proper diagnosis or treatment or as it interferes with work.
- It can impact relationships with romantic partners, friends, or family members who don't understand the disease and its effects.
- It can lower self-esteem. Many people who are uneducated about the disease, including some doctors and other health care professionals, will dismiss menstrual pain as being “normal” or claim that it's all in her head.

Can pregnancy stop the progression of endometriosis?

Temporarily. Pregnancy and the increase in progesterone levels often relieve symptoms, but they typically return after birth and/or after stopping breastfeeding.

How and why does endometriosis cause infertility?

Researchers are still trying to understand the relationship between endometriosis and infertility, but endometriosis is one of the top three causes of female infertility. Many are unaware of their infertility or endometriosis until they attempt to get pregnant. In some patients, endometriosis goes untreated, and the disease progression allows the endometrial lesions to block the fallopian tubes and inhibit ovulatory functioning. Some studies also suggest that endometriosis may alter the uterus in a way that disrupts embryo implantation, however, this notion requires more research.

Fact Sheet & Common FAQs about Endometriosis

What is the cause of endometriosis? Are you born with it?

Research is still ongoing to determine the exact cause of endometriosis, but some studies suggest a genetic component.

Can endometriosis be inherited?

With one first-degree family member affected (mother, sister, daughter), a person has an increased risk of having endometriosis.

Are there any links between endometriosis and cancer?

This is an area of research that is just beginning to expand.

Is a hysterectomy recommended for pain management?

When the uterus is removed, there is no longer any chance of becoming pregnant. EndoFound does not recommend a hysterectomy as a sound treatment option for endometriosis. Pain associated with endometriosis does not necessarily stop when a hysterectomy is completed as the ovaries continue to produce estrogen, facilitating disease progression. Additionally, lesions may still be found on other organs (perhaps unrelated to the reproductive system), which may cause symptom manifestation.

Thank you!

From The Endometriosis Foundation of America

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How to get involved:

Whether you're passionate about education, advocacy, or fundraising, we'd love to hear from you.

Interested in bringing menstrual health education to your school or community? Reach out to the ENPOWR Project at: [**enpowr@endofund.org**](mailto:enpowr@endofund.org)

Looking to start a fundraiser or make a donation to support our work? Contact our Development team: [**development@endofund.org**](mailto:development@endofund.org)

For media inquiries or partnership opportunities, please email our PR team: [**pr@endofund.org**](mailto:pr@endofund.org)

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