The Endometriosis Foundation of America (EndoFound)

## QUARTERLY REPORT



## About EndoFound

The Endometriosis Foundation of America (EndoFound) is the **nation's leading nonprofit** organization dedicated to increasing disease awareness and recognition, advancing landmark 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.

Thanks to our thousands of supporters who year after year demonstrate their generous and passionate support, we have been able to continue improving the lives of people with endometriosis. Together, we have given millions of patients a voice, successfully advocated for policy changes that prioritize menstrual and reproductive health in several states and across the world, and transformed endometriosis into a globally recognized disease of urgent scientific and social consequence.

We are deeply grateful for your continued support this year, as we work towards our collective mission to elevate the discourse around endometriosis beyond medicine, into the realm of equality and human rights.





To redefine the future of menstrual and reproductive health by transforming endometriosis from a silenced condition into a globally recognized and urgently addressed disease.

### Our Mission

To champion early diagnosis, medical education, and expert surgical training, while integrating endometriosis education into medical schools and universities, to ensure that the next generation of physicians—and society at large—recognizes a patient's pain as valid, urgent, and deserving of answers.

### Our Values

To advance science through research, reshaping cultural narratives through education and advocacy, and driving global awareness to close the historical gap in knowledge, compassion, and gender equity in healthcare.

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### A WARM WELCOME

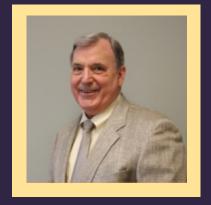
We're delighted to name **Dr. Piraye Yurttas Beim as Chairperson** of the Board of Directors. Dr. Beim has been a longtime board member and visionary innovator in women's health for more than 25 years. She is the founder and CEO of Celmatix

Therapeutics, a biotechnology company pioneering advancements in reproductive medicine, and brings nearly a decade of leadership to EndoFound and a deep commitment to its mission.



We are now at a critical juncture where philanthropic support for women's health research has never been more urgent. To bring lasting change, we must move decisively into the era of molecular insights into this disease.

—Dr. Piraye Yurttas Beim



A heartfelt thank you to **Dr. Dan Martin, who served** as interim Executive Director of EndoFound in addition to Medical Director. Dr. Martin, who has been involved with the foundation for many years, will continue his role serving as the Chair of the Scientific Advisory Board.

## A Heartfelt ThankYou

Whether it's groundbreaking research, powerful advocacy, or personal stories of resilience, our work is driven by one unshakable force: you.

Thanks to your support, EndoFound continues to inform, connect, amplify legislative efforts, and uplift this global network of hope and progress. You help us shine a light where there was once silence, bring answers where there was confusion, and build hope where there was pain.

We're so grateful to have you with us. If you ever feel called to share your story, deepen your involvement, or simply let us know what you'd like to see more of, please reach out. Together, every voice and every gift brings us closer to a world where no one has to suffer in silence.





#### Shaping the Future of Endometriosis Science

EndoFound proudly drives cutting-edge research to answer the biggest questions about endometriosis—why it develops, how we can diagnose it earlier, and what new treatments may finally bring relief to millions. For too long, doctors have relied on surgery to diagnose endometriosis. EndoFound-funded scientists are developing earlier, less invasive detection methods. They are studying the gut microbiome, analyzing genetic and molecular "signatures" in tissue and blood, and building patient-centered data tools like the Phendo app. One landmark effort, the ROSE study at Northwell Health, collects samples directly from patients in hopes of creating the first-ever non-invasive diagnostic test for endometriosis. Researchers are also pushing beyond hormones and surgery to create safer, more effective therapies. Current projects test ways to reduce inflammation, target immune pathways, and design innovative non-hormonal treatments.

Learn more about the research we fund

To date, EndoFound has invested over \$1.5 million in research grants to leading institutions such as MIT, Stanford, Johns Hopkins, and many more. These grants fuel breakthrough discoveries while encouraging young investigators to enter the field, ensuring a strong pipeline of research for the future. By supporting both senior and early-career scientists, we keep innovation in motion and moves us closer to earlier detection, better treatments, and hope for a future without endometriosis. Join us in driving research forward—your support today powers the breakthroughs of tomorrow.

Every dollar invested in research brings us closer to the first non-invasive diagnostic test and new, life-changing treatments for endometriosis. You can help.

Announcing the Seckin Endometriosis Research Center for Women's Health at Cold Spring Harbor Labratory

#### A Historic Commitment for Endometriosis Research & the Future of Care

Research has always been core to the Endometriosis Foundation of America's mission, and this April, we had the great honor of announcing the launch of the Seckin Endometriosis Research Center for Women's Health at Cold Spring Harbor Laboratory, a landmark initiative dedicated to advancing endometriosis research.

This commitment marks a pivotal moment in the scientific community's approach to studying endometriosis, one of the most debilitating and widespread conditions that affects an estimated 200 million people around the world.

Despite its prevalence and the immense suffering it causes, endometriosis has been historically under-researched and widely misunderstood. This limited understanding has resulted in a significant and long-standing unmet clinical need, characterized by substantial delays in diagnosis, invasive surgical procedures, and therapeutic strategies that are frequently inadequate or associated with significant side effects.



EndoFound Board Chairperson Dr. Piraye Yurttas Beim, CSHL Assistant Professor & Lead Investigator Dr. Semir Beyaz, EndoFound Founder and President Dr. Tamer Seckin, women's health advocate Alexis Joel, & CSHL Director of Research Dr. Leemor Joshua-Tor

Announcing the Seckin Endometriosis Research Center for Women's Health at Cold Spring Harbor Labratory

The launch of the Seckin Endometriosis Research Center is a direct response to this critical research gap and represents a historic investment in women's health. It is the first dedicated endometriosis research center within a premier U.S. basic science institution.

EndoFound's pledge of \$10 million dollars matched by CSHL Board Chair Marilyn Simons for a \$20 million total commitment—will contribute towards new diagnostic and therapeutic advances for endometriosis.

Cold Spring Harbor Laboratory

Learn more about the center



"For all the patients who have suffered silently and been overlooked for far too long, we dedicate this research center to you. We will find you the best possible diagnosis and treatment for this disease. I promise we will one day find a cure."

—Dr. Tamer Seckin, CoFounder of the Endometriosis Foundation of America

"The major goal of this Research Center is to interrogate the complex genetic and environmental determinants of endometriosis. We will investigate the precise molecular and cellular mechanisms underlying endometriosis to develop preventative, diagnostic, and therapeutic strategies. —Dr. Semir Beyaz, CSHL Assistant Professor & Lead Investigator

### One for the Cure Campaign

When Amy Schumer made a surprise appearance on stage at EndoFound's 13th Annual Blossom Ball on May 15, the actress, comedian, and patient of EndoFound cofounder Dr. Tamer Seckin instantly captured the attention of the packed room with one line: "If men had endometriosis, there'd be a cure by now."

Schumer's speech, along with that of actress and patient Foláké Olówófôyekù, triggered a social media buzz that carried outside the ball and lasted long after the event. That excitement led to the creation of **One for the Cure, a national fundraising campaign to raise \$1 million** before the next Blossom Ball in 2026.

All money will go towards the newlyestablished Seckin Endometriosis Research Center for Women's Health at Cold Spring Harbor Laboratory. Reaching the campaign goal would fund one year of that research.

EndoFound will feature several campaigns throughout the rest of 2025 and into 2026, including pop-up fundraising pushes, influencer collaborations, limited-edition merchandise drops, and virtual events such as town hall meetings with researchers and patient advocates.

#### **Donate One for the Cure**

The "One for the Cure" name stems from the idea that \$1 million can be raised by one million people each giving one dollar.



EndoFound Founder and President Dr. Tamer Seckin & Actress and Advocate Amy Schumer

## More ways to support People with Endometriosis

# Support EndoFound's Vital Work in Education, Advocacy, and Groundbreaking Research

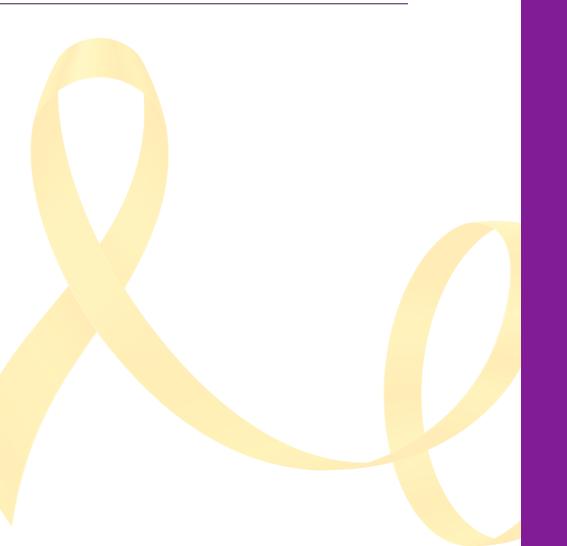
Your passion makes a difference. Whether you:

- Start an online fundraiser
- Host a community event
- Donate in honor of a birthday or milestone
- Raise awareness in your school or network

...you are a hero in the fight against endometriosis, and we're here to support you every step of the way.

Learn More

EndoAlly is a grassroots initiative empowering communities to support our mission. Whether you're passionate about raising awareness or funding research, EndoAlly gives you everything you need to start-fundraising kits, resources, and support included.





### The End Endo 5K

\* Last month, the 2025 End Endo 5K raised an incredible \$79,772.07—nearly 37% above our \$55K goal and 44% more than last year. Participants from across the country completed their five kilometers by any means they wished, whether via walking, running, bike riding, dancing, horse riding, roller skating, or kayaking. Thank you to all of our dedicated participants, who demonstrated just how much awareness can be raised for endometriosis in just one week—momentum we are determined to keep going with more fundraisers in the year to come.



Mark your calendars for the 2026 End Endo 5K on September 14–20!

"I rode 25 miles for endometriosis. I rode for me. I rode for the 190 million women who struggle every year with this horrible illness. I rode for a cure I rode for education. I rode for community."

—Kimberly Cavoores



## The New York City Marathon

Last Sunday, the 50 dedicated runners of Team EndoStrong crossed the finish line at the annual TCS New York City Marathon in Central Park. These passionate endometriosis advocates helped us raise over \$270K for endometriosis research, education, and advocacy. Thank you to whole team, all of our donors, and everyone who came to cheer them on.

Running for Team EndoStrong has always been more than just showing up on the day of the race. Clare Murphy, Team EndoStrong's coordinator, connects the runners months in advance so they can share training regimens, get to know one another, and be there to support each other. Everyone has a personal connection to the disease and a shared goal.

Next year's race will be Team EndoStrong's 12<sup>th</sup> consecutive year as a charity partner. Stay tuned for how to join the team in 2026, and if you missed your chance to support the team, **you can still contribute!** 







## EndoFound's **Signature Events**

#### **Blossom Ball**

Last May, the 13th Annual Blossom Ball lit up the iconic Pierre Hotel in New York City. Featuring powerful remarks from Fareed Zakaria, Foláké Olówófôyekù, and Innovation Award honoree Dr. Piraye Yurttas Beim, the evening brought together supporters, advocates, and healthcare leaders and renewed our shared commitment to earlier diagnoses, better treatments, and access to expert care for all. A special surprise appearance by actress and comedian Amy Schumer added laughter and authenticity, followed by a moving performance from actress and singer Lexie Stevenson.





#### **Medical Conference**

Every year, EndoFound's Medical Conference brings together the world's leading clinicians and scientists of medical care for endometriosis to explore the latest breakthroughs in diagnosing, managing, and treating the disease. This year's 17<sup>th</sup> annual international conference, "Your Mother Should Know, Your Doctor Should Know Better" highlighted the critical need for early detection and diagnosis and honored Dr. Ceana Nezhat and Dr. Paolo Vercellini for their tremendous contributions to endometriosis research and care.

### **Patient Day**

Featuring presentations by patient advocates, physicians, researchers, and key thought leaders, EndoFound's annual Patient Day provides attendees with information and resources to take control of their health and live their best lives with endometriosis. Last March, over 200 individuals from 28 states and five countries attended for a full day of learning, networking, and community support.

#### Social Media

### EndoFound's Social Media Growth Fuels Awareness, Donations, and Community Impact

Because of your support, EndoFound's social media presence has become one of our most powerful tools for education, awareness-building, and community connection. In 2025, the impact of your generosity has grown substantially.

Between February and September 2025, because you shared, engaged, and helped spread the word, our social media following grew from **45,239 to 61,200** - a gain of nearly **16,000 new followers** in just seven months. This is the fastest increase in our history and shows how deeply people are seeking accessible, accurate information about endometriosis.

Your engagement helped several posts go viral - one reaching **2.4 million views and another surpassing 1 million**. This surge in visibility has created real change: with increased organic reach driven by our community, the average ad cost per donation dropped from **\$66.67 in Q1 to \$35 by Q3,** allowing every contributed dollar to go further.

Your support also strengthens tools like our Google Ad Grant, which continues to bring thousands of people to our educational resources and programs each month.

Through regular optimization and review, we ensure these resources create maximum impact.

Because of you, EndoFound is reaching more people than ever—and making every dollar count.

Endo Found had an increase of nearly 16,000 followers in just seven months.

In 30 days, from mid-July to mid-August, the foundation's posts across all social media sites reached 2.3 million views. 1M+

Two recent posts surpassed 1M+ views, with one reaching 2.4M views and 79K likes—driving major momentum for sustained growth.

80%

80% of those views were from non-followers, signaling strong brand discovery.

Follow us on social media!



### Endo TV

#### Informing, Empowering, and Expanding Reach

Hosted by Diana Falzone, Ambassador and Executive Producer at EndoFound, Endo TV is a multimedia platform dedicated to deepening the public conversation around endometriosis and menstrual health. Through long-form interviews and educational content, it explores a range of topics including early diagnosis, fertility, pelvic floor therapy, acupuncture, pain management, integrated and holistic approaches, and complex cases.

EndoTV features a wide range of guests, including leading medical professionals, endometriosis surgeons, researchers, patient advocates, authors, and public figures who are helping raise awareness around menstrual health.

The platform has been largely supported through grant funding over the past five years and is now exploring new sponsorship opportunities to sustain and grow its impact.

Over the past three months, EndoTV has seen steady growth in audience engagement and visibility on YouTube. Notably, nearly 45% of total watch time came from women aged 35–44, demonstrating strong resonance with a key demographic. As we continue to expand our presence through daily social media "shorts," planned podcasts, and upcoming webinars, EndoTV is building a foundation for long-term, multiplatform impact.



We also want to hear from you. Let us know the topics you'd like us to cover in future episodes, and be sure to subscribe to EndoTV on YouTube so you never miss an update.

Subscribe to EndoTV

## Advocacy





## Advocacy

### The UpEndo Coalition

#### Together, We Make Endometriosis Impossible to Ignore.

Through education, awareness, and support, we are empowering patients, families, and communities nationwide.

EndoFound works every day to make sure endometriosis is **no longer overlooked.** At the national level, our team raises awareness through educational briefings on Capitol Hill, meeting and educating elected officials about the disease, public events, and coalition building. These efforts highlight endometriosis **as a serious public health issue, broaden understanding, inspire new research opportunities, and strengthen support for patients and families.** By sharing medical expertise alongside patient experiences, EndoFound ensures the disease is better understood and addressed with compassion and knowledge.

A key part of this effort is the UpEndo Coalition, which now 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.



Board Chair Dr. Piraye Yurttas Beim, Dr. Tamer Seckin, and Alexis Joel traveled to the White House to meet with CMS Administrator Dr. Mehmet Oz and senior HHS officials to advocate for the millions impacted by endo.

## Advocacy

### The UpEndo Coalition

Across the country, states also partner with us to advance menstrual health and endometriosis education. Inspired by our ENPOWR Project, many states bring menstrual health education into schools, expand training for healthcare providers, and create resources for students and families. Others launch awareness campaigns, organize study groups, and develop community initiatives that shine a light on menstrual health and endometriosis. From the Northeast to the South and across the West Coast, these efforts equip more communities with the knowledge and tools they need.

Looking ahead, EndoFound will continue expanding school-based programs, strengthening partnerships, and sharing trusted resources nationwide. Each step forward—whether through the UpEndo Coalition, a classroom program, or a public awareness campaign—offers hope to millions.

Together, we will change the way the world understands endometriosis.

"Every action—big or small—brings us closer to a future where endometriosis is no longer ignored."

Join UpEndo





## The ENPOWR<sup>T</sup> Program



The ENPOWR®Project (Endometriosis: Promoting Outreach and Wide Recognition), EndoFound's flagship educational program, was founded in 2013 with a New York state grant secured by EndoFound co-founder Padma Lakshmi. The program was crucial in the passage of a 2019 New York State law that made educational materials about endometriosis available in schools.

ENPOWR®provides those and other menstrual health education resources, including access to trained volunteer educators, which ENPOWR®continues to recruit nationally.

In December 2023, EndoFound relaunched ENPOWR® with a national focus, featuring new print materials, videos, an online course, and a streamlined system for volunteering. Since then, ENPOWR® has partnered with 59 middle and high schools in 18 states. ENPOWR® educators have delivered 92 presentations to almost 5,000 students, and an additional 600 students have completed the program's e-course. ENPOWR® has also distributed tens of thousands of print materials to schools during that time.

"All of our volunteers are such passionate individuals.

Working with them is one of my favorite parts of my job. They're taking matters into their own hands and changing the climate by spreading endometriosis awareness in their local communities."

—Carolyn Mayer, MPH, ENPOWR Program Director

## The ENPOWR Program

### ENPOWR's Core Pillars

### SHARE

Share comprehensive and age-appropriate menstrual health and endometriosis education to middle and high school students nationwide.

### **ADDRESS**

Address menstruation
stigma by fostering
widespread education and
open discussions about the
prevalence and impact of
endometriosis.

### **EMPOWER**®

Empower students to proactively seek care when needed, equipping them with self-advocacy skills and resources for tracking symptoms.

## The ENPOWR Program

According to surveys, students before & after each presentation:

## Reaching Students Impacted by Endo

**Q:** Have you ever had to miss school, practice, or an event because of your period?

 47.3% of female students responded "yes"

Students were asked to rate their comfort discussing periods on a scale of 1 to 10.

 Average scores rose from 7.8 → 9.2 out of 10 Comfort
Discussing
Periods

Symptom Awareness **56%** of female students reported one or more of these symptoms around their menstrual period:

- Nausea
- Vomiting
- Leg pain
- Diarrhea
- Heavy bleeding

The ENPOWR Program

According to surveys, students before & after each presentation:

Personal Connection to Endometriosis

**Q:** On a scale of 1-10, how likely are you to tell someone you know about endometriosis?

 Average rating increased from 6.2 out of 10 to 9 out of 10

- 21% Know someone with symptoms
- 14% Personally experiencing symptoms
- **4%** Both self + someone else

Educating
Through Word
of Mouth

\*all surveys are deidentified

Student feedback confirms the power of peer-led, classroom-based education.

## The ENPOWR® Program

## How ENPOWR impacted male students



"I have some friends that say this happens to them. Now that I know about this I can tell them what's really wrong and help them now. Rather then later."



"My mom and my little sister have had bad mood swings and have a lot of painful symptoms, and it affects their lives in a bad way. I'm going to tell them about endometriosis."

<u>Learn more about why educating boys</u> about endometriosis is critical



"My girlfriend has all of these symptoms and I'm going to convince her to see a gynecologist to see if she has endometriosis."



"My ex-girlfriend is always bed ridden for like a day. I will be sure to tell her about [endo] since she had all the symptoms."



"To be honest I've seen a friend of mine...whose periods were quite gruesome, so because of that she has stopped hanging out with us and left our group. I understand more now."

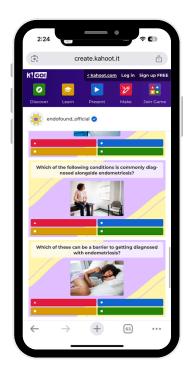
## The ENPOWR® Program

### Innovation in Action: Interactive Education Tools That Engage, Inform, and Inspire

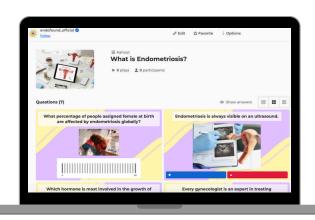
As part of our ongoing efforts to make menstrual and endometriosis education more engaging and accessible, EndoFound is preparing to launch a series of **interactive Kahoot! quizzes under the ENPOWR® program.** These educator-friendly tools are designed to support students in learning key concepts related to menstrual health and self-advocacy in a format that is fun, digestible, and easy to integrate into classrooms.

The upcoming quiz topics include: What is endometriosis?, Myths and facts about endo, Self-advocacy, and more. This launch marks a significant step forward in our mission to break down stigma and spark peer-led dialogue in school settings.

With Kahoot!'s global reach of over **25 million active users**, including more than **8 million educators**, and **11 billion+ cumulative participants** since its launch, these tools offer a powerful and scalable avenue to expand ENPOWR's impact. By leveraging Kahoot's intuitive design and widespread use in schools, we can empower more students nationwide to recognize symptoms, seek appropriate care, and feel more confident discussing menstrual health openly.







### The College Ambassador Program

Thanks to your support, the **ENPOWR College Ambassador Program** has already become a powerful force for change on campuses across the country. Launched in response to growing student demand, the initiative brings together passionate student leaders who are dedicated to raising awareness about endometriosis and menstrual health in their school communities.

These ambassadors have **hosted presentations**, **facilitated peer conversations**, **and distributed free educational materials** to **thousands** of students. Many have also shared personal stories, becoming pillars of support for peers who may be struggling with symptoms but unsure where to turn.











College Ambassadors tabling and presenting at their universities.

### The College Ambassador Program



+19

Presentations delivered across the U.S. since Feb. 2024



+33

College Ambassadors representing 31 campuses in 20+ states



+18,500

Materials shared in the past year alone



+5,500

Students educated through 90+ in-person presentations this year

Pre- and post-survey data shows **significant increases** in student understanding of symptom onset, prevalence, and recognition.

The College Ambassador initiative reflects ENPOWR's broader mission: to make menstrual health education **accessible**, **accurate**, **and youth-centered**. With every event, presentation, and conversation, these student leaders are breaking the silence and building a more informed generation of endometriosis advocates, one campus at a time.

Learn more about how ENPOWR continues to grow

### The College Ambassador Program

What the inaugural '24-'25 cohort is saying



"I **thoroughly enjoyed** this year and being able to represent such a great organization with a great mission."



"I **enjoyed being** able to **advocate** for a cause that I care deeply about and also being part of a supportive environment!"



"I spoke about endometriosis and medical gaslighting [on campus], as well as explained my endo story, and spoke about menstrual cycles. I even had someone tell me that they think they may have endo, as a lot of the symptoms I explained aligned with what they experienced during their periods."



"I enjoyed learning [about endo] and being able to share that information with others!"

#### Some of ENPOWR'S Milestones



Provided Nurse Education to the Valley View School District in Illinois.



Partnered with PERIOD.ORG to provide endometriosis materials for school health kits in Miami and Portland.



Hosted a table at the 17th Annual Black Women's Wellness Day in Madison, WI to share free endometriosis education resources.



Gave an assembly presentation at Dolores Huerta Middle School with Mara Wilson for the entire 7<sup>th</sup> grade class of approximately 350 students.



Program Director Carolyn Mayer & Endo Educator Izzy Wegner held 10 presentations in a single day at Benjamin Cardozo High School, reaching approximately 300 students.

## Closing





### **LOOKING AHEAD**



- Giving Tuesday December 2<sup>nd</sup> 2025
- Every Story Matters Campaign December 2025
- Capitol Hill Advocacy Day March 2026
- 18<sup>th</sup> Annual Patient Day March 2026
- Together for Tomorrow Campaign March 2026
- Blossom Ball Spring 2026 (date tbd)
- 18<sup>th</sup> Annual Medical Conference May 2026
- End Endo 5K September 14<sup>th</sup> 20<sup>th</sup> 2026
- TCS NYC Marathon November 2026





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## Thank you!

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#### **Contact Information:**

www.endofund.org

212-988-4160

872 Fifth Avenue New York, NY 10065



#### 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@endofound.org

Looking to start a fundraiser or make a donation to support our work? Contact our Development team: **development@endofound.org** 

For media inquiries or partnership opportunities, please email our PR team: **pr@endofound.org** 

