

endofound.org



ENDOMETRIOSIS FOUNDATION OF AMERICA

The nation's leading nonprofit for endometriosis

Impact Report 2019-2020

End Endo:
EndoFound's Next Decade

EndoFound

Programs at a Glance

Awareness

We are breaking down the stigmas and taboos surrounding endometriosis and menstrual health, particularly talking about periods. We provide content through our annual medical conference, patient conferences, webinars, social media, our website, and growing partnerships with other organizations. Together, we are making endometriosis a household name.

Education

EndoFound seeks to educate both the public and medical professionals about endometriosis. Our school and community-based education programs have educated countless high school students in over 21 states, six countries, and growing. Our annual medical conference offers a forum for endometriosis experts worldwide to share the latest medical and research information on the disease.

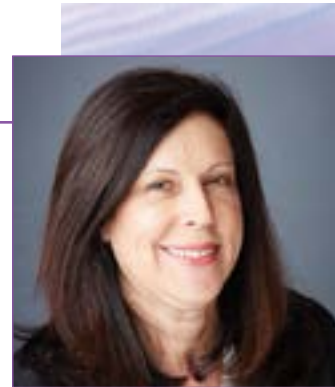
Research

EndoFound has awarded over \$1 million to research, so the healthcare community can better understand the disease to deliver improved diagnosis and treatment strategies. These studies are published in top journals including *The New England Journal of Medicine*, garner distinguished awards, and have served as seed funding for NIH grants.

Advocacy

Our advocacy team continues to fight for change across local, state, and federal levels. Our efforts helped to pass the first U.S. Menstrual Education/Endometriosis law in New York State and have been instrumental in supporting #Upendo, the first endometriosis caucus in the U.S. House of Representatives.

Letter from the Executive Director



Dear Endometriosis Community,

When a young girl comes to her mother, school nurse, soccer coach, or anyone else she hopes might listen, she's looking for help. Her period pain may be excruciating and she feels like no one understands her pain. She's told, "It's something all girls go through." Her doctor tells her the pain is in her head.

For Merve, it took nearly 20 years for doctors to diagnose her endometriosis. Once diagnosed, she said, "I don't know how I would have survived and continued living a close to normal life if I didn't have other women talking about endometriosis."

For EndoFound co-founder Padma Lakshmi it was decades before she was diagnosed. For Halsey, Molly, Diana, Merve, Eileen, Claudia, Kaila, and so many thousands of other individuals who suffered for years with endometriosis, we thank you for your courage to share your stories.

By sharing your journeys, you pulled back the curtain on this disease, leading others to seek care sooner. You built a robust community to lead us into the next decade with a clear mandate: more funding for education and awareness, better diagnosis, more research dollars, better treatment options, and someday, a cure.

With **landmark legislation** requiring menstrual health disorders, including endometriosis, to be included in materials provided to schools and medical practices in NYS, and the launch of the **House Endometriosis Caucus** spearheaded by another courageous woman, Congresswoman Abby Finkenauer, the needle is moving in the right direction. As you read this letter, the US Senate will be deciding if they will support the House bill passed in July to increase endometriosis research funding to a **precedented \$26 million**.

But our work is far from over, and our plans for the next decade include taking ENPOWR virtual, implementing the NYS legislation in every state, ensuring that the House Endometriosis Caucus can secure more research dollars, and creating a National Endometriosis Awareness program.

It is because of you and your support that EndoFound is where it is today. I am in awe of your courage, thank you for your support, admire your determination, and I am inspired by your kindness in reaching out to one another to build strong communities.

I know in the next decade we will see even more strides in endometriosis care. Together we can end endo!

In community,

A handwritten signature in blue ink that reads "Margaret Caspler Cianci". The signature is fluid and cursive.

Margaret Caspler Cianci

History Timeline

Co-founded in 2009 by Dr. Tamer Seckin, and a group of his patients, including Padma Lakshmi, EndoFound has been a leader in bringing national awareness to endometriosis as well as funding important research. The last decade has seen tremendous strides made in endometriosis education, awareness, advocacy, and research.

- Dr. Tamer Seckin and a group of his patients, including Padma Lakshmi, co-founded the Endometriosis Foundation of America.
- Dr. Harry Reich is honored at the **1st Annual Blossom Ball**. Master of Ceremonies is Fareed Zakaria and featured speaker is Whoopi Goldberg.
- **EndoFound partners with MIT** to launch a gynecopathology research facility, the first of its kind, devoted solely to investigating women's reproductive health issues, including endometriosis, uterine fibroids, and polycystic ovarian syndrome (PCOS).



- EndoFound hosts the **1st Annual Lunch & Learn Nurse's Conference** with Padma Lakshmi.

- EndoFound hosts the **1st educational endometriosis training** at Kips Bay Boys & Girls Club in the Bronx.



2009

2010

2011

2012

2013



- EndoFound hosts the **1st Annual Medical Conference and International Symposium**.

- EndoFound co-founder Padma Lakshmi visits the New York State Senate to launch the **Teen Health Awareness Campaign** with NYS Senator Jeff Klein to educate on endometriosis, substance abuse, and obesity.
- **NYS Senator Klein & Padma Lakshmi** announce \$250,000 in funding to support an education campaign aimed at raising awareness around endometriosis statewide.
- EndoFound launches the **Endometriosis Nation Promoting Outreach and Wide Recognition (ENPOWR) Project**, a community-based adolescent endometriosis education program.

- EndoFound participates in its first **NYC half marathon**.





- EndoFound hosts the **1st Annual Patient Day**, created for and inspired by patients and featuring world-renowned researchers and physicians, nutritionists, management practices, and patient advocates.
- The 1st ENPOWR Award** is given to NYS Senator Jeff Klein and The Young Women’s Leadership School. Subsequent awards are given to the Brooklyn Latin School (2016), Stephanie Morris (2018), & Marymount School of NY (2019).

- EndoFound announces its **first research grants program**.
- EndoNews, The Blossom, and EndoStories** go live, providing endometriosis news and patient stories.
- Breast, Ovary and Endometriosis Medical Conference** is held in October in recognition of Breast Cancer Awareness month to examine the relationship between breast cancer and endometriosis.



2014



- The Research Outsmarts Endometriosis (ROSE)** study partners with Feinstein Institute of Medical Research to explore the origins of endometriosis.
- The National Symposium for the Advancement of Women in STEM** is held at Harvard University.
- The 1st Harry Reich Award** is established, recognizing extraordinary healthcare professionals making a difference in women’s lives by their practice, research, and advocacy.
- EHE International**, a recognized leader in preventive medicine, donates the **Rockefeller Center Window Display** to EndoFound with the slogan, “Killer Cramps Are NOT Normal.”

2015

2016



- EndoFound launches the **Endo EduKit** to bring critical education to students across the country and around the world.
- Padma Lakshmi** visits Capitol Hill for a lunch-time briefing in the Hart Senate office building, which was only one stop during her packed day of lobbying (also on her daybook were meetings with lawmakers, including senators Chuck Schumer, Elizabeth Warren and Kirsten Gillibrand).

2017



2018



- International singer and songwriter **Halsey** is honored at the **Blossom Ball**.
- Dr. Tamer Seckin** and patient advocate **Diana Falzone** visit Capitol Hill for a Congressional briefing and to visit the offices of **Senators Orrin Hatch & Elizabeth Warren**.

2019/2020 Milestones + Achievements

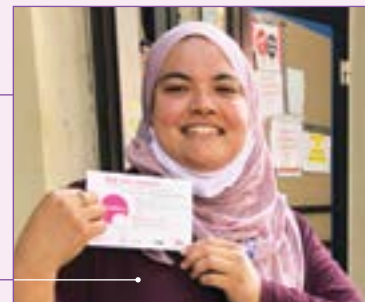


Our two-year advocacy in NY state resulted in bi-partisan legislation amending the health law to include menstrual health disorders, including endometriosis. This law is the first of its kind in the U.S.



Our support for Congresswoman Abby Finkenauer and the first-ever **Congressional Endometriosis Caucus** led to the U.S. House of Representatives passing legislation to increase endometriosis research funding from \$14 million in 2020 to \$26 million in 2021.

COVID-19 struck the world hard, and the pandemic lockdown and subsequent economic downturn left many girls and women without period supplies. **PeriodNow.org** prioritizes ending period poverty and educating about endometriosis.



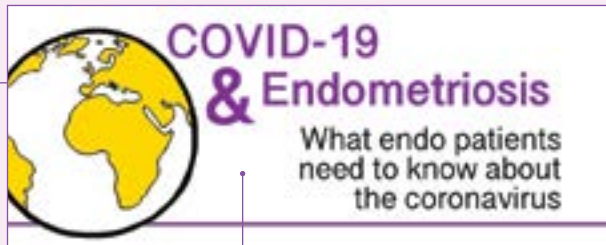
EndoFound awarded **over \$1 million in research grants** to over 30 leading research institutions. Four awardees received subsequent funding from the NIH to further their endometriosis research.

In response to a nation in crisis, we built comprehensive resource portals for **Endo Patients & COVID-19**, the **LGBTQIA Endo Community**, and the **Endometriosis Resource Portal for People of Color**.





As the world went virtual, so did EndoFound with a series of webinars including the **Mind, Body & Soul Strengthening Wellness Workshops** and the **Candidly COVID-19 & Endo** series.



COVID-19 & Endometriosis
What endo patients need to know about the coronavirus



We held our first **Virtual End Endo 5K**, raising over \$30K and spreading endometriosis awareness.

Healthline voted EndoFound's "**Blossom**" one of the **Best Endometriosis Blogs for 2020** saying, "This web portal is chock-full of rich information for anyone who wants to learn more about endometriosis."



We welcomed **Margaret Caspler Cianci** as our Executive Director.

EndoFound hosted the **10th Anniversary Blossom Ball** honoring **Fran Drescher** (Lifetime Achievement Award), **Alaia Baldwin Aronow** (1st Annual Horizon Award) and **Molly Qerim Rose** (Blossom Award).



Research Grants

The federal government gave only \$13 million to endometriosis research in 2019, despite 1 in 10 U.S. women* having the disease, equating to less than \$1 per year for each diagnosed patient.

Although the disease continues to be critically underfunded, there have been some recent victories, such as Congresswoman Abby Finkenauer's #UpEndo campaign and EndoFound's research grants program, which has paved the way to larger grant funding from the National Institutes of Health. Read below about four researchers who were funded by EndoFound.



Dr. Ie-Ming Shih

Dr. Ie-Ming Shih and his team at Johns Hopkins received several grants from EndoFound to pursue cancer-associated mutations in endometriosis, leading to a research grant from the NIH for approximately \$3.5 million in July 2019.

“This NIH grant is made possible at least in part by the continuous kind support from EndoFound that enabled researchers to generate the preliminary results that were used to successfully compete for this grant. All the researchers in this grant express their sincere gratitude for the Foundation and all the EndoFound donors who make this possible.”



Dr. Leslie Farland

An EndoFound grantee, Dr. Leslie Farland at the University of Arizona Health Sciences, received a \$442,000, two-year grant from the NIH to study the association among endometriosis infertility and stroke risk.

“The support from the Endometriosis Foundation of America has allowed my research program to expand our expertise on endometriosis and cardiometabolic endpoints. With the support of the EFA, we were the first study to prospectively investigate the relationship between endometriosis and risk of type 2 diabetes using data from over 100,000 women in the Nurses' Health Study II. This work on diabetes has allowed us to receive future funding from the NIH to continue to support research on endometriosis and comorbid conditions.”

**Our definition of “women” includes transgender, genderqueer, and non-binary individuals.*



Dr. Katherine A. Burns

Dr. Katherine A. Burns at the University of Cincinnati College of Medicine received two EndoFound grants, subsequently receiving two NIH grants in 2019/2020.

“I am thrilled to be a part of the Endometriosis Foundation of America (EndoFound) and to have research funding from the EndoFound. EndoFound is shedding such a light on endometriosis and allowing women to have a voice. I’ve had so many people come to me having seen commercials on TV regarding endometriosis. The disease is being recognized; however, there is still a long way to go to understand what this disease is, how we can treat it, and how we can prevent it from happening in so many young women. I am glad to share my story whenever I can, but I lived for years thinking I was the only one with this disease. I am proud of EndoFound for giving awareness to young girls to help them understand that living in pain is not normal.”



Dr. Anna Pollack

Dr. Anna Pollack at George Mason College of Health and Human Services was an EndoFound research grantee in 2018. She studied endocrine-disrupting chemicals, a project which formed the basis for a \$1.6M grant from the National Institute of Environmental Health Sciences (NIEHS).

“This grant was critical in providing the preliminary data to apply for a larger grant from the NIH. We’re leveraging stored tissue samples from the eutopic endometrium as well as from ectopic endometrium tissue samples which will be measured for a range of chemical exposures. This will really provide us with a way, uniquely for the first time, to evaluate the dose of these chemicals at the target tissue.”

Medical Conferences

EndoFound believes educating the next generation of medical professionals and collaboration amongst researchers and clinicians brings us closer to a cure!

We are proud to have sponsored the following international endometriosis conferences:

- *Stem Cells and Excision Surgery*
- *Let's Talk About Sex and Endometriosis Seriously*
- *Tapping the Roots for the Next Generation*
- *The American Perspective*
- *Politics, Ethics, and Controversies*
- *Ending Endometriosis Starts at the Beginning*
- *Pursuing Precision with Passion*
- *Breast, Ovary and Endometriosis*
- *Targeting Inflammation: from Biomarkers to Precision Surgery*
- *Reoperative Endometriosis*

To Our Donors – Thank You!

Women and girls are community leaders, entrepreneurs, educators, business leaders, now even Vice Presidents of the United States, and so much more. For years, research has shown that investing in women and girls has ripple effects through a community.

At EndoFound, we are eternally grateful to everyone who has supported the endometriosis community over the last decade. We appreciate all of you who have donated and volunteered more than you know. EndoFound could not do what it does without the generous support of a caring community!

Donate

We know that you share our goal to help the 200 million individuals who have endometriosis. It also has been a challenging time for fundraising, and we understand that many causes need your support. Please consider donating to EndoFound in your year-end giving so that we don't lose critical momentum in endometriosis research and so that we can continue to elevate disease awareness and support women across the country suffering from this disease.

Thank you!

Donate online: endofound.org/donation

Our privacy policy: endofound.org/donor-privacy-policy

Sign up for our newsletter: endofound.org

“That feeling of validation I had been seeking for so many years had finally come to fruition, and it would not have been made possible without having found the EndoFound website. I finally, with EndoFound's help, had validation to receive gold standard treatment that ideally should be accessible to all that are in need. EndoFound also was able to lead me to find different ways to manage my disease post-surgery. They recommended the top care, and it led to the best results I could have ever asked for. EndoFound is an organization that works to increase disease recognition, provide advocacy, facilitate expert surgical training, fund landmark endometriosis research, but most importantly, change lives, like they have mine.”

– Leslie Patriarco

“I first ran for Team EndoFound to honor the women I know with endometriosis, so that through EndoFound's educational outreach efforts others wouldn't have to wait years like they did for a diagnosis. When a complete stranger told me that my fundraising messages (spread through social media) got her to ask her doctor about endometriosis, and it was because of that she finally got a diagnosis, I understood just how much more educational outreach still needs to be done.”

– Robert Frederick

Our Team + Board members

Founders

Tamer Seckin, MD
Padma Lakshmi

Board Members

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Tove Wood

“EndoFound has created national and global awareness on endometriosis and has made millions of individuals feel less alone. Along with advancing research, surgical methodology, and education, EndoFound has been a key force in tackling the taboo on menstruation and women’s health: periods are not shameful, women’s health cannot be underfunded, and we can tackle this disease together.”

– Dr. Tamer Seckin

Staff

Margaret Caspler Cianci,
Executive Director
Jeanne Rebillard,
Director of Communications & Strategic Engagement
Sarper Kocabiyik,
Director of Technology
Melissa Boudreau,
Director of Marketing and Outreach
Diana Falzone,
Director of Media Relations and Advocacy
Ayse Ayhan, MD, PhD,
Editor of EndoNews
Mina Seçkin,
Communications Associate & Editor of The Blossom
Deniz Kocas,
Research Advisor
Rachel Grobman,
Social Media Coordinator
Charlotte Varcoe-Wolfson,
Project Associate

Scientific and Medical Director

Dan Martin, MD



Endo Fast Facts

- 200 million women worldwide have endometriosis; 1 in 10 women has endometriosis.
- The average time to diagnosis is 7-10 years.
- Nearly 75% of women* with the disease experience a misdiagnosis.
- Women with a close relative with endometriosis are 4 to 7 times more likely to also have the disease.
- An estimated 25-50% of women with infertility and 71-87% of women with chronic pelvic pain have endometriosis.
- Endometriosis can impact all aspects of a patient's life – school, career, finances, relationships, and overall wellbeing.

There are a number of ways to contribute:

- Donate
- Volunteer
- Organize a fundraiser
- Join the conversation on social media
- Partnerships
- Sponsorships

Visit endofound.org to learn more



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872 Fifth Avenue
New York, NY 10065
212-988-4160

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