



**EXTRAPELVIC
NOTRARE**

INAUGURAL ANNUAL NEWSLETTER

EXTRAPELVICNOTRARE.ORG

" WHERE SCIENCE MEETS COMMUNITY "

OUR MISSION

"Educate, Advocate, Conduct and Support Research for Endometriosis as a disease with body-wide lesion potential and capacity to disrupt systemic homeostasis."

With deep gratitude of the time and talents invested by our team of volunteer's, it is a delight to share the inaugural EPNR Newsletter with you.

What a journey it's been! But, in cosmic terms, we're just getting started.

Only a few years ago, the very mention of endometriosis in areas like the ureter, diaphragm, or liver, provoked knee-jerk reflexive statements like, "It's too rare". Glances by healthcare professionals suggested you were from another planet!

I know, I hear you; it's still happening. The topic of endometriosis being located outside of the reproductive area is as foreign to medicine as aliens to humans. But ever so slowly, the conversation is changing.

The interest in, and awareness about, extrapelvic endometriosis has grown by leaps and bounds in recent years! An ever-growing number of testimonies and requests for information about extrapelvic endometriosis continues to refute claims of its 'rarity'. This has been a reinforcing catalyst to continue our mission. Extrapelvic endometriosis isn't alien, it's simply under-acknowledged, under-represented, and is an under-investigated portion of a heterogeneous disease that has been falsely labeled a homogeneous, gynecological condition.

From the toil of others before and alongside us, EPNR emerged from necessity. It transpired from my own lived experience and recognition of barriers that construed endometriosis to be only gynecological. We want to drive more awareness, more education, and more research. That is why we are here!

- Wendy Bingham, DPT - Founder & Executive Director, EPNR

[More About EPNR](#)

WHAT IS EXTRAPELVIC ENDOMETRIOSIS?

"Pelvic endometriosis is defined as endometriosis lesions involving the uterus, fallopian tubes, ovaries, and the surrounding peritoneum, the anterior and posterior cul-de-sac, and pelvic

Endometriosis

- has been found in all
11 major body systems

Reproduction
Digestive
Urinary
Excretory
Cardio-Vascular
Pulmonary
Muscular
Skeletal
Neurological
Cutaneous
Lymphatic
Skeletal



sidewalls. Extrapelvic endometriosis is described as endometriosis-like lesions elsewhere in the body" Markham (1997)

SUPPORT EPNR

2023 Gluten & Dairy Free Recipe Calendar



SPECIAL OFFER

BLACK
Sale
FRIDAY

\$15 each

SHOP NOW
@endoividualeats.com

PURCHASE LINK

BLACK FRIDAY - CYBER MONDAY
2023 Endoividual Eats Monthly Calendar
\$15
(incl. postage anywhere in the world)



EXTRAPELVIC
NOTRARE



Together
we give.

Nov 29, 2022

GIVING
TUESDAY

GIVING TUESDAY

Please see our social pages for more
information OR donate today!

DONATE TODAY

DONATE ALL YEAR-ROUND

**Cyber Monday and Year-
Round Purchases**

AMAZON SMILES



**All contributions are tax-deductible for the current year
(participating countries)**

PARLEZ VOUS ENDO?

We're going multilingual!

Our goal is to provide evidence-based, unbiased information in multiple languages. Through the blessing of volunteers, who are fluent in other languages we will be able to reach more people.

We can't provide translated material in every language but we will strive to translate portions of our website starting with French, German and Spanish.

This is an exciting venture for EPNR. The rollout of translated material will begin with our social media content along with the website reconfiguration by the end of 2023 or early 2024.



- Editing Newsletters/Press Releases
- Events Management/Donations
- Website Development/Design
- Marketing Management
- Fundraising (Events)
- Graphic Design
- Grant Writing
- Copywriting
- Social Media
- Translating

vol•un•teer

/völən'tir/
agent of change



Sign-Up to Volunteer

EDUCATION

Endometriosis

Established Perception,
The Reality,
and Need for Revolution



Wendy Bingham, DPT

Endo: Not Just Bad Pain Tour
28, March 2022



Extrapelvic Not Rare



March 2022: Endometriosis Association of Iceland - Guest Speaker, Founder Wendy Bingham: 'Not Just Bad Pain Tour' Reykjavik, Iceland

Audience: Iceland's Minister of Health and Members of the Icelandic Parliament, the general public

The Endometriosis Association of Iceland rocks the world! This dedicated group created and executed an incredible event with the mission to educate members of Parliament, the Ministry of Health, and medical professionals about the realities of endometriosis: the disease, life with the disease, and current issues of access to excision surgical care. These ladies presented facts from every angle, giving their representatives adequate information concerning the socioeconomic, life quality, and inadequacies compared to other health conditions. I am SO proud of them and honored to stand with them in pursuit of the best care.

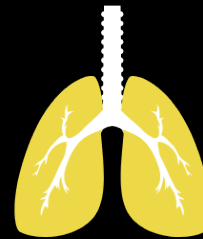
ADVOCACY



"Previous studies of endometriosis among identical and fraternal twins estimate genetic expression is responsible for about 50% (47%-51%) of endometriosis characteristics; the remaining results from environmental influences"

***Heritability of Endometriosis. Fertility and**

RESEARCH



Our first research project is
underway!



"Survey of a select population of persons with surgically diagnosed thoracic/diaphragm endometriosis and their medical encounters from symptom onset through surgical diagnosis".

Analysis of collected data and draft manuscript of EPNR's first research study is underway. We are aiming to submit and publish the study in Spring 2023. EPNR aims to develop and submit our second research study to IRB by the end of 2023.

More About Our Events



COMBINED SALEM WOMEN'S EXPO & SALEM HEALTH & WELLNESS EXPO

OUR FIRST LIVE BOOTH Salem, Oregon, January 2022

Join Our Extrapelvic Endo Community

