

***This is why we need to continue working together to find answers and a cure:***

I am a member who has experienced post hysterectomy endo recurrence. The surgery was over 25 years ago. For many years after my surgery, my symptoms did not subside and I had to continue taking very powerful medications for quite some time with many disturbing side effects. I finally found a compounding pharmacist who worked with my doctor and I was given progesterone suppositories and my condition improved dramatically – no side effects.....\*

Two years ago, it started to return. I had a laparoscopy and had numerous adhesions removed. The photos taken showed lots of little yellow dots around the adhesions. My liver was banded to my hip. After the surgery, all my symptoms recurred. I am 56 years old.

By the way 4 doctors (including the surgeon) said I didn't have endo because it doesn't come back. I wish the women my age would remember our Association when their daughters are crying during their menses. I know the memories are painful but it's more painful to witness someone you love go through it.

***Diana, WI***

***\*Editor's Note:*** While progesterone suppositories or crèmes have been useful to some, it is not a simple approach for all women with endo as many are allergic to progesterone and there are other considerations. Please see our books for discussion about this topic.

Thank you for the material you sent regarding drs. working w/endo. My daughter (now 57 yrs. old) has suffered with it all of her life & has had several operations. The promise of permanent help has not come from them. FYI dr. discussed her present sad condition (she is on strong pain patch medication) at some length on phone and said he didn't have the skill to attempt laparoscopic exam. So many of the drs. on your list are fertility specialists.\* My daughter has been thru the mill. . . . What can we do?

***Marjorie, PA***

***\*Editor's Note:*** Many of the physicians who treat endometriosis are indeed fertility specialists – they have been interested in endometriosis far longer than physicians have been interested in the pain, and assisted reproductive technologies has become a very big business. Marjorie is correct that those focused on fertility typically aren't helpful for pain.

Dear EA, Thank you for linking me up with the New York Endo group. We had a meeting 21<sup>st</sup> March and in several ways it was an eye opener for me. For the first time I was in a group of the most sympathetic people. They have all been there and sincerely know about the struggles people with endo go through.

I have registered with the Endo Association. I became a member about a month ago. I found the package sent to new members very educative and highly helpful! Thank you. I would appreciate any assistance that can be given me in respect of starting an Endo Association in my community. Tips, ideas or samples to follow would be helpful; pamphlets, medical information and other forms of information that would help get people educated and give hope would be greatly appreciated. I have resolved anyway to help my community any way I can.

***T. O., Nigeria***

My daughter had endometriosis and was diagnosed a couple of years ago. We have the photos of her orange-sized tumor that they removed. For years she was told it was all in her head, she needed [psychological] therapy and several of the doctors misread the scan until one really knew what he was looking for. I think she suffered on and off for at least 5 years. You would think that this had happened 50 years ago, but unfortunately not.

***A scientist and father, NC***

I've had it for 21 yrs. I was able to handle the pain until I turned 50. My last 2 cycles have been unbearable. My legs, back, abdominal and pelvic area all hurt so bad.

***Deborah, MS***

Hello, Mary! My name is Mackenzi. I am 24 years old and was diagnosed with endo through my first laparoscopy about 6 years ago, although I have been suffering the pain for nearly 12 years. I have had 4 laparoscopies, a neurectomy, multiple birth controls, Lupron Depot, and "special diets." None of these have helped my pain for more than a couple months. What really aggravates me is that nobody, including doctors, seems to know anything about this horribly painful disease. I have wanted to be a member of the Association for some time now, but being a stay at home mom I really don't have the money (even though the fee is very reasonable).\*

***Mackenzi, WI***

***\*Editor's Note:*** The Association used to have the funds to provide gift memberships when individuals were destitute – certain criteria had to be met. The current recession has wiped out our ability to do that.

Dear Mary Lou, Please accept this check as a small donation toward "the cause." A few weeks ago, I finally tired of giving to everyone else's charities – arthritis, melanoma, cancer walks, etc. so I started teasing my friends that, "no one ever gives to my charity!"

So, when the woman next door ran a fundraising yard sale, I set up a cotton candy machine and sold bags and sticks of it for four hours on a sunny Saturday. Please know I hope to send future donations once my friends open their wallets!--or when I set up the cotton candy machine again!

***Nancy, MA***

***\*Editor's Note:*** Anyone interested in doing fundraising and wanting tips and support, please contact Headquarters to talk with Ellen, our Development Coordinator. She will also assist in putting you in touch with our Vice President of Fundraising and others.

To Whom It May Concern: Enclosed is a letter I sent to [an advice columnist] along with a copy of the column I was responding to. I was angered by the idea that women would spend \$300 million dollars on cosmetic surgery when so little is being done for women's diseases in general and endo in particular. It also angers me that there is more information widely available about where a woman can go for cosmetic "improvement" than about where a woman can go if she is suffering symptoms of endometriosis. I think that far too many of us have suffered in silence for far too long. I know I have and I intend to talk about it to anyone who will listen. It's too late to help me, but maybe it won't be too late for our daughters and granddaughters.

***Brenda, VA***

I've been dealing with this pain for almost two years now at varying degrees. The pain slacks a little and then gets worse. I've missed work and have lost jobs because of this. I may lose my current job now. I've heard of other people with endo having this sort of thing happen to them. I'm guessing this is normal. I feel very alone with the mental and emotional stress of not knowing what I have or what is causing it.

If there is any sort of support group in my area, I would be grateful.\* I have requested a free info packet from your website. Thank you for reading this.

***Christine, Nova Scotia, Canada***

***\*Editor's Note:*** Currently, we have not been able to fund to any great degree continuing development of support group. We hope to learn more about making our groups effective as we currently are restructuring our Support Program – however we do need financial support!