

It takes an average of 8 doctors and 10 years to be dianosed with endometriosis.

## You can help change lives.

# HOW TO USE THIS TOOLKIT

THANK YOU for helping girls in your school & community. You join thousands of nurses & educators across the U.S. who are enacting this program. Together, we can change lives.

**OUR** primary goal is to help you recognize endometriosis symptoms & encourage girls to seek appropriate care. Research shows that school nurses are usually the first to know when a teenage girl has symptoms. As early recognition & diagnosis are key, you play a pivotal role.

THIS toolkit shares facts & ideas on how you may make the greatest impact in your school & community.

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**WE'VE** partnered with some of the world's foremost experts from Harvard, Yale, Stanford & many more to put this resource together. However, it can't stop there. Simply put, we need you to make it happen.

YOU CAN lay the groundwork for lasting change. We can end the devastating narrative of endometriosis. You can lead the way.

> Shannon Cohn Director/Producer

of Endo What?

I hope our daughters Live in a world with early diagnosis & effective treatment for endometriosis.

# hope for our daughters

## NURSE EDUCATION INITIATIVE

### THIS IS A SOCIAL ACTION CAMPAIGN

inspired by the successful film ENDO WHAT? We've sparked an international movement to change girls' lives by spreading widespread awareness. THE POWER OF THE PROGRAM lies in the participation of nurses like You who work each day to create healthy schools & communities. By using this Special Edition DVD and Toolkit, you are part of this extraordinary movement!

# WHAT YOU NEED TO KNOW

ENDOMETRIOSIS IS A CHRONIC, SYSTEMIC DISEASE where tissue similar to the lining of the uterus grows outside the uterus.

This misplaced tissue develops into lesions which respond to the menstrual cycle in the same way that the tissue of the uterine lining does: each month the tissue builds up, breaks down, and sheds. This results in internal bleeding and inflammation causing pain, infertility, scarring, adhesions, and bowel problems.

EARLY DETECTION IS KEY. Due to a lack of awareness and misinformation, it takes an average of 10 years & 8 doctors to be diagnosed. Unfortunately, complaints of pain are not always taken seriously by healthcare providers.



### **TEENAGERS ARE NOT TOO YOUNG TO HAVE**

ENDOMETRIOSIS. An estimated 1 in 10 girls & women have endometriosis so you absolutely know girls who have it.

ENDO IS AN INVISIBLE ILLNESS. Girls may look healthy, but still experience excruciating pain & other symptoms.

PERIOD PAIN IS NOT NORMAL. A subtle discomfort during periods is normal, but severe pain that interferes with a girl's life is NOT. 70% of girls with chronic pelvic pain have endometriosis.

# ENDOMETRIOSIS IS NOT AN STI. A girl can NOT

catch it. The cause is unknown although we know that genetics, hormones, diet & exposure to certain environmental toxins may play a role. The girl did nothing wrong to have it.

There are other symptoms beyond pelvic pain. A girl may have ONE, ALL or any COMBINATION of these:

### SYMPTOMS

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- Severe period cramps (pain so bad that she can't do
- her usual routine for hours or days at a time)
- Heavy periods
- Bloating, nausea, diarrhea or constipation, pain with bowel movements (could be constant or may come & go with periods)
- Frequent or burning urination
- Pain with exercise or activities
- Fatigue
- Pain with sex

### HOW YOU CAN HELP A GIRL WITH ENDOMETRIOSIS:

**PROVIDE SUPPORT** & a place to rest when the pain is flaring. It's important to track symptoms and times of the month. If the pain and/or symptoms are cyclical, there should be a strong suspicion of endometriosis. That said, she may have pain during her period, at other times of her cycle or every day of the month.

**PROVIDE INFORMATION** & resources to educate her about the disease. A good place to start is with the online resources in the back page of the toolkit.

**HELP MAKE ALLOWANCES** to support achievement of her academic goals. Talk with her about what she can tolerate in school and what she just can't manage.

**CLASSMATES, FRIENDS AND FAMILY** need to know & understand what she's going through. Encourage her to communicate with her support network.

#### **TEACHERS, COACHES AND/OR ADMINISTRATION**

need to understand that her pain is a real medical condition. Educate them with information about endometriosis, including the film + toolkit.



### REFER HER TO A HEALTH CARE PROVIDER to explore

her symptoms further. Be aware that the majority of providers may not be accurately informed about endometriosis. Be prepared to help further direct her to other accurate resources.

### PUT THIS TOOLKIT INTO ACTION



WATCH THE FILM.



#### HANG THE ENCLOSED POSTER

in your infirmary so that students may see it & start to learn about endometriosis. An easy way to instantly spread awareness!



### **READ THE FACTS** about Endo & Symptoms Checklist

in this Toolkit so that you can quickly & easily recognize them in girls who come to see you.



# **SHARE THE DVD + TOOLKIT** with your school administrators & health teachers. We

have a ready-made Lesson Plan for Health teachers on our website (www.EndoWhat.com).



#### **INITIATE THE CONVERSATION.**

If you think a student has endometriosis, suggest she explore her symptoms with a health care provider.

\*Unfortunately, many healthcare providers do not know the symptoms of endometriosis or erroneously believe teenagers can't have it. Follow up with the student & encourage her to reach out to some of the resources on the next page.



### **FEEDBACK?** We'd love to hear from you at nurses@endowhat.com.

# FOR MORE INFORMATION ABOUT ENDOMETRIOSIS

### VISIT OUR WEBSITE ENDOWHAT.COM

ENDO GIRL TALK endogirltalk.org

ENDOMETRIOSIS RESEARCH CENTER endocenter.org

ENDOMETRIOSIS FOUNDATION OF AMERICA endofound.org

ENDOMETRIOSIS ASSOCIATION endometriosisassn.org

#### **GROUPS ON FACEBOOK**

ERC Girl Talk Endo Warriors Nancy's Nook Endo Metropolis