

PCOS NEWS

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Support In The City!

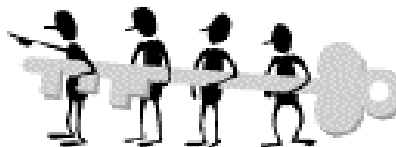
In our biggest turn out to date, the PCOS Study enjoyed an informative talk given by Dr. Ellen Greenblatt. Many interesting questions were asked and answered. Also, women were happy to have the opportunity to meet their fellow study participants. We are planning for another meeting in the future. Please e-mail us your ideas for what you would like to see at upcoming support group meetings.



Study Update

**Overall, 54 Women Have
Now Been Enrolled!**

**Each one of you plays a key
role in our quest to unlock the
answers to our questions!!**



WORDS TO LIVE BY

**“When you get to
the end of your
rope, tie a knot
and hang on”.**

**- Franklin Delano Roosevelt, 32d
U.S. President (1882-1945)**

MEDICAL FORUM

SHEILA LAREDO, M.D.

PCOS - A Woman's Perspective



There is very little information available about what women with PCOS know about their condition, and how they feel about it. Despite the fact that many of the symptoms of PCOS can result in significant stress to women who have it, there have been no studies to address these concerns.

A recent group undertook a study in which women were asked 15 questions. (Sills et al BMC Women's Health 2001). The questionnaire was targeted to women with PCOS, and was posted on the Internet. It isn't clear that all the respondents necessarily had PCOS, but based on the responses it is likely that many did. If you are curious, the questionnaire can be accessed at this web address: <http://www.obgyn.net/cfm/pcos-survey/pcos-survey.cfm>

Of all people who viewed the site in one month, over 40 % responded to the questionnaire. The majority were young (26-34 years old), and over 60% had previously taken fertility medication at least once. Interestingly, the greatest concern by far in this sample was infertility (over 60%), with only 16% naming weight problems as their main issue. Over 80% of the people first heard of PCOS from their health professionals. Despite this, half of the respondents consulted their specialists first about PCOS, and just over one quarter used the Internet as their first line of information.

Most interestingly to me, when women were asked to describe their feelings about having PCOS, 66% described frustration, and 16% chose anxiety as the major feeling attributed to their diagnosis. Only 1.6% of women felt indifferent about having PCOS.

One of the problems with this study is that we cannot be certain about the population who answered the questions. It is likely that this is a generally well-informed and well-connected group because they have access to the Internet, found the site and have successfully accessed medical services. Over 80% of the women had received health care in the last 6 months, and over 40% for infertility, again supporting the likelihood that this does not necessarily represent the "average" woman with PCOS. Given this, it is interesting that even within this likely better-than-average informed group, only 61% considered themselves to be "very aware" regarding their level of understanding of PCOS, and 12% considered themselves to be "minimally aware" or "not aware at all".

While this study is a beginning at understanding the feelings and perceptions of women with PCOS, much remains to be answered. Health professionals tend to concentrate on the medical aspects of the condition, but we sometimes forget to

deal with the human and emotional aspects of it as well. Based on this study, it appears that the emotional aspects of PCOS need to be carefully and sensitively addressed. One of the things that we are doing as part of the PCOS Diet & Exercise Study is looking at women's perceived health status using a questionnaire that has been used in a variety of other health conditions, but not yet in PCOS. It will give us our first information about whether health status in women with PCOS is different from comparable Canadian women, and whether it can be changed with lifestyle interventions. We look at both the physical and mental aspects of health in this questionnaire. This will not answer some of the questions about feelings women have about PCOS, but it will be a start in that direction. We have been impressed in our discussions with many of you by the ways in which PCOS can affect various aspects of your lives, and we feel positive about the fact that we will be able to get a sense of the extent to which this affects your overall health status.



The Devil Made Me Do It!

Vanessa R. Speers, M.Sc.

Do you hear voices? No, I mean the ones that are really there. The voice in your mind that seems to be telling you what to eat (usually something not on your healthy weight program) and when to eat it (usually all the time). It's time to talk back and take control. We need to be conscious of this voice to stop the negative directions that we hear and exchange them for positive thoughts and actions.

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| <p>Go ahead. Eat it. It's only one piece of chocolate.</p> | <p>I know that one piece can lead to another and I want to stop this binge before it starts!</p> |
| <p>You're fat. You've always been fat. You always will be fat.</p> | <p>I may not have been born with the kind of genes that allow me to eat everything in site and never gain weight, but I have all the tools I need to know what my body can handle and I chose to eat the foods that will result in a thinner and healthier me.</p> |
| <p>It's a special occasion. You can always start tomorrow.</p> | <p>I have today. I have now. I don't know what tomorrow will bring, but I can make choices today that will contribute to my health because I only have one body and I know what to feed it!</p> |
| <p>So, what makes you think that you can keep the weight off this time? You never have in the past.</p> | <p>I've made up my mind to treat myself with respect and dignity. The first thing I'm doing for myself is not listening to you! The past is past. Today, I am a new person.</p> |
| <p>The scale is up one pound today. It's over. You might as well quit.</p> | <p>There are lots of reasons that the scale can fluctuate on a day-to-day basis. I'm only going to weigh myself once a week and I'm going to keep track of my weight. I will see a pattern and not let a number on a scale sabotage that good work I am doing for myself!</p> |
| <p>You've already eaten 10 pieces of candy. You might as well eat the whole bag.</p> | <p>I can stop myself now because "falling off the wagon" doesn't mean I have to stay off the whole day.</p> |
| <p>Skip lunch. Then you can eat twice as much at dinner.</p> | <p>I know that if I skip lunch I will be ravenously out of control at dinner and eat four times as much food.</p> |
| <p>You haven't lost any weight in two weeks you. You will never reach your goal.</p> | <p>I know that weight loss plateaus occur along the way but, sticking diligently to my plan of healthier eating and exercise will allow me to break though the plateau and eventually reach my goal.</p> |

Be Informed About Lifestyle Change

Vanessa R. Speers, M.Sc.



Why is lifestyle change emphasized in the PCOS Study?

If you were gaining weight — or maintaining a very high weight — with your previous diet and exercise patterns, you will need to acquire a different set of patterns to achieve long-term weight loss success. It is that simple.

Bottom Line: Learning and using behavior skills will help you successfully lose weight and keep it off.

What is it about my lifestyle that needs to change to improve my weight?

There are countless challenges at work and home to divert our good intentions of eating well and staying active. The pressure to eat surrounds us at the same time our lifestyle makes it increasingly difficult to spend calories. Simply being aware of the social triggers to eat too much is an important first step to develop a successful approach to lifelong weight management. Our ideas can be added to those of your own. Try to find a few key changes in eating and activity that will make a big difference.

Bottom Line: Making a few key changes in your life can help you successfully lose weight and keep it off.

I can't change my lifestyle. I'm not in control.

Control is an illusion. No one has control. What we have is choice given circumstances. We can influence circumstances by our choices, but we cannot control them.

What you may really be saying is "I can't tolerate the expected outcome of making a different choice". This is sometimes a reasonable conclusion. What are the expected outcomes you fear? Emotional vulnerability, conflict with another, physical discomfort or a change in self-perception? Any of these, and more, can be intolerable at certain points in one's life. If this is true for you, consider what you can do to make the shift more tolerable. Maybe setting smaller goals in the beginning or enlisting more support would help. Sometimes the best way to make progress is to confront your fears head-on by actually making some changes.

Bottom Line: Look for opportunities to choose, not control.

I don't want to change. Change is too hard.

Yes, change can be hard. Take it in stages. Set small goals at a time. Don't overwhelm yourself with looking too far ahead. When it is most difficult **one day at a time** is a good affirmation to adopt.

Bottom Line: Take small steps.

I don't want to change. I have too much to lose.

This again is a choice. It is important to acknowledge that what you want most may not be weight loss, a healthier diet or a higher level of physical fitness. You may like your life just the way it is, and be satisfied with your health at this point in time. No one here can honestly tell you change is for the better. We don't know this about you.

But, what we can say is that if somewhere down the road you change your mind, we are here to help.