

XVI. Appendix I

Summary of Investigation on the Forum

Forum from Breast Cancer Community (<https://community.breastcancer.org/>)

- people are seeking for advice on **whether to reconstruct breast** (“Forum: Living Without Reconstruction After a Mastectomy [1,143 Topics 40,840 Posts](#)”, “Forum: Breast Reconstruction [9,981 Topics 285,166 Posts](#)”).
- People are curious about **the surgery** itself (“Forum: Surgery - Before, During, and After [6,664 Topics 179,610 Posts](#)”)
- People are looking for information on **which therapy to take** (“Forum: Chemotherapy - Before, During, and After [6,553 Topics 469,980 Posts](#)”, “ Forum: Radiation Therapy - Before, During and After [3,097 Topics 115,482 Posts](#)”, “Hormonal Therapy - Before, During and After [6,249 Topics 139,339 Posts](#)”)
- People want to learn about **treatments** (“Forum: Complementary and Holistic Medicine and Treatment [2,530 Topics 53,450 Posts](#)”, “Managing Side Effects of Breast Cancer and Its Treatment [3,023 Topics 67,020 Posts](#)”)
- Uncategorized issue (“Forum: Lymphedema [4,754 Topics 68,654 Posts](#)”)

Forum: Living Without Reconstruction After a Mastectomy

Topic Title: I look for other flat chested women. A rant. ([4,112 Posts 104,603 Views](#))

(Excerpted from the post) “I know many of you wear prosthesis, so I probably wouldn't be able to see or 'know', but. I look for you. I want to see you. I want to form a union, lol. I wish it were even more accepted, acceptable to be flat. To not wear prosthesis, not feel the need to, to opt out of reconstruction-if that is your choice. I do hope that women who see me, flat as can be, see there are options, that reconstruction isn't par for the course. I want to make flat beautiful, sexy, stylish. Normal. And it is normal for me, is becoming normal, but I am talking about society, norms and expectations. Breast cancer is not about 'boob jobs'. Yes, many of us opt for them, want and need them. But it is also about choosing to be flat.

Geez, would I like to meet up with other flat chested women. **I would love to take over a hotel, make noise, laugh, cry, be flat together-to see you. I want to meet other women who, like me, have decided not to reconstruct.** I want to be able to see you and high five! I want to experience our society of normal.”

Forum: Breast Reconstruction

Topic Title: Exchange City. (39,335 Posts 807,469 Views)

We love to include everyone's surgery dates - Please PM me and I will update the list to include you! The list keeps changing since we try to move forward as the dates move forward. Thanks. -

Jean

Useful websites:

Mentor: http://www.justbreastimplants.com/implants/mentor_specs.htm

<http://www.mentorcorp.com/breastsurgery/reconstruction/breast-implants.htm>

Mentor ultra high profile implants:

<http://www.mentorcorp.com/global/physician-information/silicon-gel-breast-implants.htm>

Allergan: http://www.allergan.com/assets/pdf/natrelle_catalog.pdf

2015: (Long list of date-username-Exchange surgery (completed))

10/5 - Pharmergirl - Exchange Surgery (completed)

...

AnnieAlso - Revision Sister in Waiting!

Forum: Surgery - Before, During, and After

Topic Title: Housework support group!!???!! (12,491 Posts 120,396 Views)

<https://community.breastcancer.org/forum/91/topics/730136>

Okay I am having trouble motivating myself to get my housework done. I had a bilateral mastectomy in October and since then I have been sorely lacking in getting things accomplished. **I do have spurts from time to time but am needing some kind of support to get focused and motivated. Anyone interested in having a one room challenge?** Just post here and tell which room your choosing then for the accountability part post back when you have that room done. Peer pressure can work wonders so I'm posting my bedroom as my one room project for this morning.

Forum: Radiation Therapy - Before, During and After

Topic Title: Radiation recovery (14,734 Posts 249,283 Views)

<https://community.breastcancer.org/forum/70/topics/774143>

Hi I know there is another thread but I thought, **since it is 60 pages old, I would start a new one for those of us just finishing radiation.** My hope is that we can discuss remedies to avoid, tight skin, discuss the emotional side of being at this point of treatment, continue to support one another and keep in touch.

Forum: Hormonal Therapy - Before, During and After

Topic Title: For Arimidex (Anastrozole) users, new, past, and ongoing **(13,816 Posts 357,541 Views)**
<https://community.breastcancer.org/forum/78/topics/790338>

I found a couple of older threads about Arimidex, but they covered a large time span with a gazillion posts, so I thought I would start a new thread for Arimidex/Anastrozole users.

I am starting on Anastrozole today. Plan is to take it for 5 years, possibly longer. I already have osteopenia and osteoarthritis (limited to one knee at this point), so I am most concerned about the bone and joint side effects. I'm already frustrated by finally having some energy and stamina back after chemo and radiation, but now I have trouble exercising due to the bum knee. I'm concerned about that getting to be even more of a problem on the Anastrozole.

Please share your experiences, side effects, questions etc. about Arimidex/Anastrozole here.

Forum: Chemotherapy - Before, During, and After

Topic Title: Hair Hair Hair - Another question **(24,300 Posts 871,915 Views)**

I know that there have been several threads on this, but I'm asking the question again: on average, when did your hair start growing back in after chemo????

I'm 4 weeks out from my last AC and any positive encouragement (and "you're almost there" posts) would really make this week wonderful.

Forum: Managing Side Effects of Breast Cancer and Its Treatment

Topic Title: Cold Cap Users Past and Present, to Save Hair **(18,005 Posts 387,736 Views)**
<https://community.breastcancer.org/forum/6/topics/735873>

Hi all, I wanted to start a forum for all us that are using the cold caps to try to save our hair. I am on FEC100 X3 followed by Taxotere X3. My dosage unfortunately is not a guaranteed success. I am 40 days out from my first treatment and will have my third June 17. So far I have thinned but have not required a wig. I have no bald spots; however, around my right ear is the thinnest. I think because the cap wasn't tight there. All in all, I am pleased to still have a good covering. **If you are using or have used the Cold Caps, I would love to hear your experience.**

A summary on breast cancer community forum:

1. Most popular posts are **looking for experience**, i.e. cold cap users to save hair, hormonal therapy, radiation therapy. Hormonal and radiation therapy started their new thread on experience sharing because there has been **too many old posts** in the past few years.
2. Chemotherapy want to hear **encouraging words**
3. Household support group wanted to start a **one-room challenge** to motivate themselves to do housework.
4. Both reconstruction and flat breast forum has a **"real-life meetup"** post as the most popular one.