The Journey Behind the Innovation.

What to Expect When You're Expecting Nipples.

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December 31, 2016

I would like to introduce my hero story with an article that I wrote for the Huffington Post in 2015, as I was just starting to develop my case studies of breast cancer patients opting for reconstruction.

Empowering Breast Cancer Patients With Pre-visualization Tools.

http://www.huffingtonpost.com/marianne-angelo/empowering-breast-cancer-_b_7562560.html

Whenever I hear about a new Breast Cancer diagnosis, I wince. I know all too well about the challenges ahead as I've been through every assault.

Someone said to me "look on the bright side, at least you get free plastic surgery!"

Most people don't delineate the two. Reconstructive surgery is much more emotional and challenging as it has everything to do with rebuilding yourself from the inside out.

In addition to focusing on the cure, I was very concerned about what my body was going to look like afterwards. I'm a single parent and worried the results would leave me with a negative body image.

I took a poll from a few breast cancer forums. "How many went through breast reconstruction not knowing what you were going to look like after surgery?" 98% said that they had no idea or wished they had known more. 2% said they knew and a few said that they didn't care.

I remember my surprise during preliminary discussions about my breast reconstruction. I only saw pictures of other peoples' results and maybe one or two pencil diagrams showing where the scars would be. That's all I had to go by to connect the dots of what my body was going to look like. I'm from the art world, a creative professional who envisions results for clients. It was unsettling to walk down the medical path without any visual references about what I could expect for my own body.

After a fourteen hour surgery, it took me a week before I could look down and assess the damage. I started to photo-document my body in effort to chart my transformation. I was very skilled with photoshop, the image-editing software. Confronting my scars close-up was sobering but once I got past the initial blow, switched into problem solving mode. I knew what needed to be done. I started drawing onto the images of my body and creating projections of what I thought I would look like at the end of a 2 year journey. I still had a year of surgeries ahead of me so I addressed all of my concerns and even found new ones.

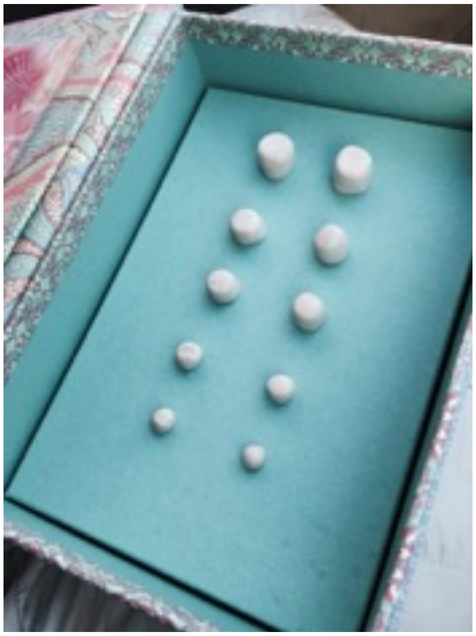
After completing the projections, I realized what I had done. I had given myself what I've been wanting all along from the medical world, information about what I was going to look like after surgery. If I had something like this at the beginning, it would have given me greater peace of mind.

I was excited to share this with my reconstructive surgeon. I asked if my projections were within scope of what I understood of his surgical direction and he promptly said yes and mentioned that it was actually very helpful for him as well. It worked both ways. I was helping myself cope and I was helping my surgeon to visually understand my expectations.

The final surgery involved nipple reconstruction. In the meeting with my surgeon we discussed the size for my new nipples. He motioned with his index finger and thumb "How about 3mm?"

When I got home I pulled out a metric ruler. I found some clay from my daughter's art supplies and started to sculpt a 3mm nipple. I held it up to my nipple-less breast and looked into the mirror. It didn't look right nor did it feel right. I started making more clay nipples in varying sizes, holding them up to my breast until I found the size that felt closest to my original nipples. 9mm felt right.

I found a glittery stationary box in my daughter's room and arranged the nipples neatly in the box. I brought them with me to the surgery. When I opened the box I caught a few reactions from the surrounding medical staff. Their jaws dropped. I held up the size that I wanted and showed my surgeon. "I think this is more me." He smiled and nodded in approval.



Box of nipples

Overall, I was very happy with my results. Going into surgery knowing what I could expect to look like after was game-changing. As a patient of Breast Cancer, it gave me a sense of control where there is very little control.

The entire experience made me passionate about improving how women cope as they go through Breast Cancer. I've seen far too many poorly reconstructed breasts in breast cancer forums where women can only speak with despair that they didn't get what they were expecting. Being happy with the results of surgery is not an elective.

Today we have the technology to ensure that every woman undergoing reconstruction takes a shared visual journey with her surgeon that reflects what she wants as well as what her surgeon has in mind for her. It's my goal that pre-visualizing surgical results becomes part of a patient-centered protocol for reconstructive patients. I'm currently developing a Breast Cancer Pre-visualization app in effort to humanize how women go through Breast Cancer.

So far, the physicians I have demonstrated it to have been very supportive. But there's too much bureaucracy to overcome within the medical infrastructure itself. It's not an insurmountable task, it's actually within the power of humanity to offer something like this in the world of Breast Cancer. So now I am now working complimentary to the medical industry. I currently have 25 patients in my pipeline all over the world who are going to experience the shared journey that I did.

Now there's a choice. You can either go on a trip with a map or without one.

— End of HuffPo article

The case studies helped me figure out how to turn BC Pre-vis service into an app to automate the retouching process so that when the service moved from patient centric to surgeons using this service it would be a quicker and more efficient way to scale.

The process of connecting with women from all over the world who wanted a pre-vis before their surgery was very exciting. I assumed a mentorship role as I had been through it and I could talk on many levels with them offering authentic support. Helping them because extremely helpful for me as I was still coming to terms with my own experience and the fall out from breast cancer. I liked that I could be a beacon on hope to these ladies and give them something that they wanted and not just talk about the process. Taking on this project helped me heal myself in many ways.

I was excited to receive news from my patients that even their surgeons thought that the pre-vis was very helpful and that the assessments were very close to expected results.

I had some interest with a few plastic surgeons in Los Angeles who worked at the big institutions but then that somehow their interest dissipated. I wondered if it worked better for surgeons to give less information than too much. Or maybe it would make for too much work for them.

The responses that I was getting from just the general public was very encouraging. Most people couldn't believe something like this wasn't already in place and applauded the steps that I was taking to raise awareness that a service like this exist in the world of breast cancer. But the silence from the medical community made me think that if I could make this into an app that a surgeon could easily use then perhaps they would be more keen about giving their patients more relative and useful information.

I started to map out the UX flow for an APP for BC Pre-vis. I wasn't going to be deterred because I know first hand as a patient that there are gaps in the medical realm that could be closed up and create better experiences for those going through treatment for cancer.

In addition to my hero story I wrote a second article in April 2016 about one of my case studies, a woman named Sheila who was brutally mutilated by her plastic surgeon while opting for a prophylactic bi-lateral mastectomy as she carried the deadly BRCA gene that took her sister. I wrote this article hoping to gain awareness for her predicament, that sometimes just liking your plastic surgeon based on a 10 minute introduction isn't enough. What came from this story was very positive.

Patients Can Impact The Breast Cancer Patient Education Act

https://medium.com/cancer-communication-research/patients-can-impact-the-breast-cancer-patient-education-act-387d6d7bf78f#.b8xwdkjo8

Sheila before surgery.

As a breast cancer survivor and advocate for those considering reconstruction, the intention to write Sheila's story wasn't to frighten future patients from acting *prophylactically as great results happen far and wide, but results like Sheila's are preventable. Patients should have the option to know what they can expect for their own body so that they can make the right choice for both procedure and plastic surgeon. When stories like this surface, it's a call to action and the patient community can impact surgical protocol for the better.*

How can you tell if your plastic surgeon's aesthetic is right for you?

What if architects only described what they were building with hand gestures? What if they only showed their clients photos of their previous buildings without showing models, site plans or elevation drawings? The client would have no idea what to expect.

It's interesting to view the surgical protocol through another top ranking professional protocol's lens. For plastic surgeons, proof of a visual aesthetic is portrayed in before and after photos of their patients. Proof of a visual aesthetic is paramount, even more so when it's your body. But the question begs, what can patients expect for their own body when all they see are photos of other patients results? For patients who aren't visual, how do they connect the dots?

Here's why pictures of other patients results are not enough.

I met Sheila in one of the many private breast cancer forums on Facebook, where women discuss prophylactic measures and share their results with those on a similar path. When I saw her photos along with fragments of her story, my heart sank. I wanted to understand how she ended up with results like this and also wanted to see if I could help her.

Sheila did her due diligence. **Pre-surgery**, Sheila knew what she wanted: A skin sparing, non-nipple sparing Prophylactic Bilateral Mastectomy (PBM) and to have results much like the ones presented to her when she met with the plastic surgeon. She was in good health and confident about the surgical direction.

Sheila recalls "Both the surgeon and his nurse reinforced how much I would like having symmetrical breasts. They would be lifted and firmer." She trusted in the plastic surgeon and that he did this procedure often. Sheila was aware that it wasn't going to be a straight arrow to desired results. A few scars, tattoos, and implants so that she could avoid a hereditary cancer diagnosis, like the one that took her sister.

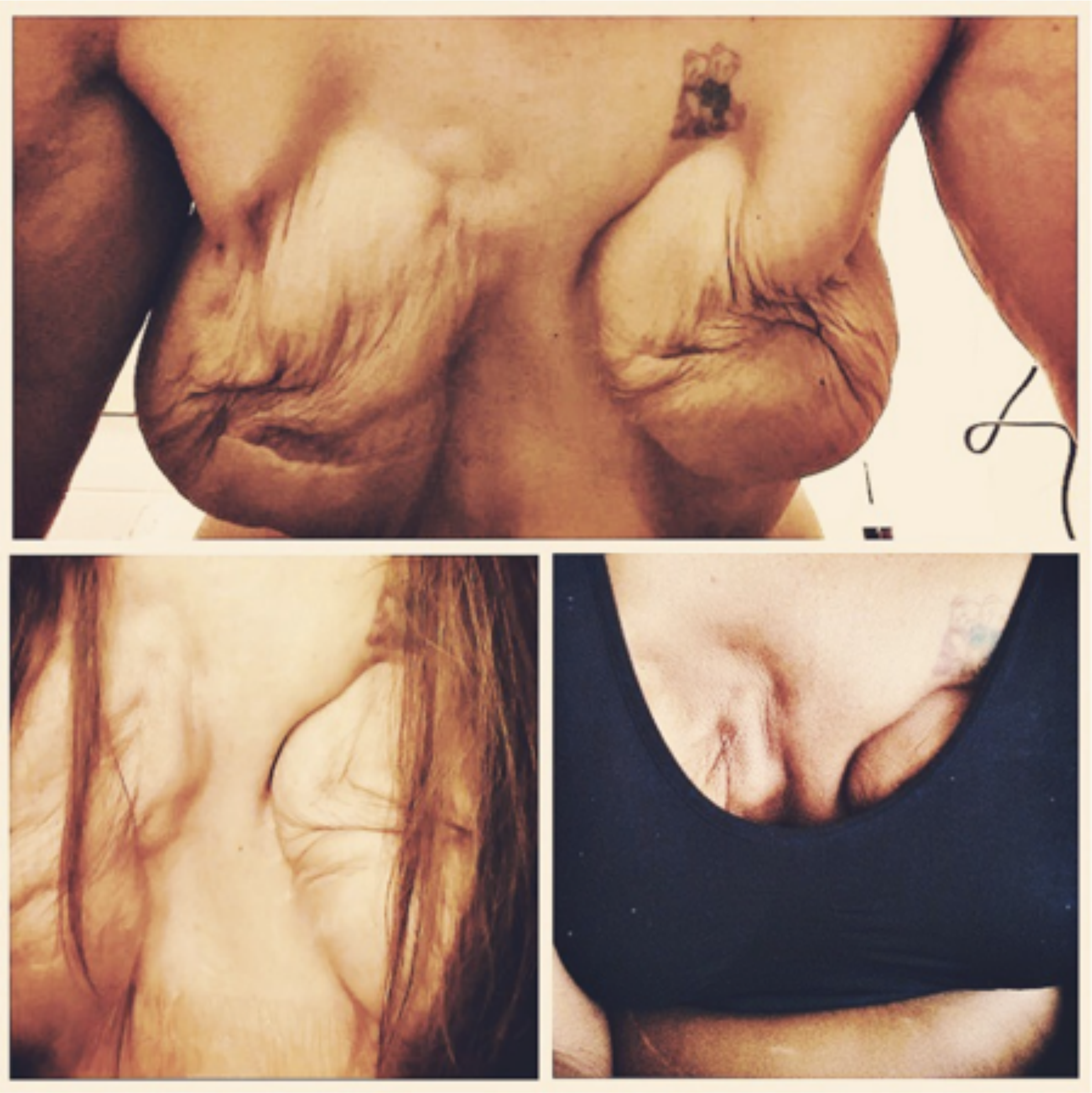
So what went wrong?

Her first surgery was 8 hours. Afterward, her plastic surgeon found her husband in the waiting room and told him the good news. "The surgery went very well and we were able to save the nipples!" The surgeon was excited but met with her husband's confusion as he knew his wife wanted them removed for extra measure.

Her body was starting to reject the expanders. An infection started to form on her left breast and she headed back into surgery to have the expanders removed and the implants put in.

She remembers "When I woke from surgery I heard screaming and did not realize that it was coming from me! I felt a burning fire sensation down the center of my body." She didn't understand how this surgery could have been even more painful than the first.

At a follow-up meeting with her surgeon, he removed her gauze bandages to inspect the new breasts. Sheila caught her first glance and tears started rolling down her face as she tried to catch her breath.



Sheila after surgery.

The surgeon read her expression, "I'm disappointed that you're disappointed." Her husband at her side, holding her up as her legs went weak. The surgeon offered hopeful advice, "Give it some time, it'll get better. Just try to wear a bra and push them together more." As he was leaving the examination room he added, "You may also want to get some counseling. Perhaps your expectations might have been unrealistic."

She never heard back from the plastic surgeon, which was just as well. Her disappointment led her to find a new plastic surgeon which she traveled 100 miles to meet. After the surgeon viewed her imaging and examined her body she explained "It looks as if the pectoral muscles were cut. This is why the implants are free floating as there's no pocket." She also suggested that her ribs were likely broken during the procedure. On top of everything, Sheila found out that her new insurance provider didn't cover part of her surgeons fees as he was not on the new network and was stuck with a large out of pocket expense.

How could the system have worked better for Sheila?

Even though Sheila was presented with quality photos of the surgeon's results for other patients, and was told what she could expect to look like, she did not come close to the results presented in the plastic surgeons examples. Perhaps if he told her that she could end up disfigured by going through with this surgery, she would have had the chance to walk away and find someone else.

Sheila's Rule! is a petition to ask the Secretary of Health and Human Services to consider adding to the education campaign they are currently planning titled the Breast Cancer Patient Education Act, that plastic surgeons provide examples of projected results of what patients can expect for their own body so that results like Sheila's can be averted.

The Breast Cancer Patient Education Act is to inform breast cancer patients of the availability and coverage of breast reconstruction and other available alternatives post-mastectomy. This Act can do more. Information is education and patients who participate in their care can leverage their results for the better. **Please sign the petition that will make this possible.**

— End of Medium article

The wonderful thing about writing on the Medium platform vs. Huffington Post is that I can track analytics and see how many people have read the article and on what day they read it. I shared this article on Facebook and Twitter and within 2 days the article was shared over 300 times and over 18,000 people read it within the span of a week.

Sheila was so distraught that she was contemplating going onto the show Botched to expose this surgeons poor work and gain attention to hopefully fix her situation. She couldn't find any qualified surgeons in the stated of Indiana who would take on her case, so she resorted to the notorious show *Botched* out of complete desperation. I thought that she could do better and that's in part why I wrote her story. She needed a reconstructive surgeon who does this work day in and day out. I had inquired with my surgeon at UCLA to consider helping her but never heard back. I also suggested that she consider the reputable NOLA Center for Restorative Surgery since every result that I've seen from that group of surgeons was impeccable and that it was closer to where she lived. She said that she couldn't afford to go out of network and that she was stuck with Indiana surgeons or prayed that the Botched show would picked her up and fix her pro-bono.

But something so serendipitous happened and that's why platforms like Facebook and Twitter are so remarkable. When Sheila's story was shared on Facebook a surgeon found the story on one of his previous patients home page and inquired with his patient about the story. This surgeon happened to be one of the top surgeons at NOLA's Center for Restorative Surgery, the place that I had recommended to Sheila earlier. This surgeon then reached out to Sheila and kindly offered to fix her gratis. I couldn't believe Sheila's good fortune. And relieved that she didn't go on the show Botched. She would have never ended up with such results as these. I was very proud of the actions that we both took to get her back to herself.

I was lucky to meet Sheila's reconstructive surgeon Dr. T. What a mench. A truly wonderful soul. He accepted my invitation to give Sheila a Pre-vis, one that I would work on with him so that he could present it to Sheila. I felt that Sheila has been through so much already that a pre-vis would help ease her anxieties about another surgery and reinforce trust in her new surgeon. She needed to heal from the mental scars of being mistreated and this was the first step. So we worked together. He thought the pre-vis was awesome as they were his notes and when he presented it to Sheila she cried and couldn't believe it. She went from a surgeon who showed her his best case scenarios for breast augmentation (which a prophylactic bi-lateral mastectomy is not) to a reputable surgeon who showed her what he was planning for her surgery with visual examples on her own body.

And that's how it should be.

Sheila 1 week after surgery.

Sheila 2 months after surgery.

** Sheila's Pre-vis example will be attached to application.*

I feel so passionately that this type of service exist for those in the unfortunate place of having to consider breast reconstruction brought on by breast cancer. I've actually created a petition addressed to the Secretary of Health and Human Services Sylvia Mathews Burwell hoping that she will connect the dots that his is an educational tool for patients and surgeons and incorporate it into the newly forming Breast Cancer Patient Education act.

https://www.change.org/p/sylvia-mathews-burwell-patients-can-impact-the-breast-cancer-patient-education-act

After this triumph I decided that I needed to go back to making this into an APP for surgeons and while still keeping it a service for patients because I enjoy mentoring breast cancer patients. I'm currently considering partnering with a reputable plastic surgeon in Los Angeles who has a private practice and will work with me to develop the app as an educational tool not just for patients but also for plastic surgeons.

I love my hero story because it keeps evolving into something greater. This will improve how women go through treatment for breast cancer so they won't have to face surgery in the dark again.

I am Marianne. I advocate for women with breast cancer and their right to know what they can expect for their own body prior to surgery.

www.bcprevis.com