

# A Caregiver's Journey with Cutaneous Lymphoma

As shared by Meredith

My Mom, Gabrielle deHart Schwarz Haab, had cutaneous T-cell lymphoma (CTCL), mycosis fungoides. She'd been going to her dermatologist and internist for years and was told she had psoriasis or hives. It was only when an ulcerative lesion developed on her leg that she was sent to an oncologist – she was diagnosed with late stage 4 CTCL. What the heck was this? We'd heard of breast cancer but not CTCL. Despite our fear, we were reassured that if you had to have a cancer, this one was manageable like diabetes.

Mom started treatments but unfortunately went through them pretty quickly. While the treatments sort of worked, the cancer was aggressive. In 2011, Mom went into the hospital in early December and we were given a last best option: to try a drug that was in clinical trial. We were all in shock wondering how we had gotten to this point and yet we were so thankful for the research and new medicines being developed. The medicine worked a miracle and bought us some time. Mom was able to celebrate Christmas in the hospital with Dad and our whole family. She was happy and able to open gifts and even worried that she didn't have anything for us (Mom loved being Santa Claus). But that year, my family got THE best gift we'll ever receive – we got Mom.



## EVERY DAY INFORMATION NEEDED

Within a week, Mom went from the hospital to skilled nursing care in a continuing care community with fewer developing skin lesions and ulcerations. And in a few more weeks, Mom came home and we were together for another 4 months. During Mom's time at continuing care and at home, my family and I realized we needed every day information for CTCL skin care that wasn't readily available to "lay people." Very little seemed written for me, the caregiver, in step wise instructions that I could follow in a difficult time. For example, I constantly worried and wondered: What do we do to get stuck bandages off lesions without causing too much pain? Could Mom be given pain meds before or during bandage changing?

As it turned out, the answer was yes. Mom was able to receive pain meds before and during bandage changes to decrease her discomfort and anxiety. Doctors and wound care nurses told us to use Vaseline®, apply it liberally around the bandage, and then apply warm compresses to loosen the bandages. This definitely helped but still, I often couldn't get the bandages off with any ease. This was my nightmare: I was causing Mom pain by being her caregiver and changing her bandages! By this time, it took a nurse and myself or my sister-in-law hours to remove, clean, and redress the ulcers and lesions. Hard times...

## IF I COULDN'T GOOGLE IT...WRITE IT

And yet...(big sigh)...and yet...out of adversity came inspiration. Mom and I had a moment of grace that we recognized and clung to: I'll never forget the moment. It came to me, seemingly out of the blue: I needed skin care guidance written for the caregiver about everyday living situations – in lay language – and I needed it now. If I couldn't Google it – Mom told me to write it. So, Mom and I started our research as a team. We would discuss and document each step we took doing skin care so that others would have stepwise directions to follow. Mom gave me permission to photograph her skin care to have visual pictures too. No one would have to figure everything out anew each time – always reinventing the wheel – alone.

Mom and I had a purpose bigger than ourselves and it felt good, even a little hopeful. Mom and I were a team. And then we ran into a problem very quickly – how to get our information out there for others to see and use? What type of legal or medical issues were involved? Was this something I could just blog about or did I need more professional support since I'm not a medical professional? What to do, what to do? After all our progress – everything came to a sudden stand still and was put on hold. And even worse, Mom was starting to get more ulcerative lesions again.

## REACHING OTHER CAREGIVERS

One day my school's dear librarian, Marti T., sent me to a site she found: the Cutaneous Lymphoma (CL) Foundation's website. My brothers and I were immediately drawn in and read everything on the website...but still, no practical instructions on how to help care for loved ones with CTCL. Hmmm. I had an idea....I called Susan Thornton, the CEO of the CL

Foundation. I asked if by any chance she'd meet me for lunch – I had an idea to run past her. She immediately said yes and I asked: Can you help me reach other caregivers? We caregivers learn by necessity, on the job, and often alone. Could she help me start talking and sharing skincare techniques from professionals, caregivers, and patients? Susan again and always immediately said “yes, yes, yes” – and that’s how the Skincare Corner in the CL Foundation newsletter was born! I ask two or three medical professionals a skin care question per newsletter (questions crafted by a board of medical professionals that Susan brought together for this purpose) and then we publish their explanations/answers for everyone to see. *[This section has since been retired from the newsletter but the questions and answers are available on the website under “Skin Care / Itch” resource page]*

In keeping with Mom’s and my vision, I’d like to share with you how we learned to remove her most stubborn bandages expanding on the professional guidance we’d received. This worked for us but you should consult with your physician before trying anything new. You can find the step-by-step recommendations on the Foundation’s website at [www.clfoundation.org/lesion-care](http://www.clfoundation.org/lesion-care).

## **LOOKING BACK**

Looking back, nothing was perfect. Mom and I learned through trial and error each step of the way. I did the best I could. I regret the times I wasn’t patient or gentle enough. I regret the times I did what had to be done when Mom really didn’t want anything done except to be left alone and have me sit down and just be with her. But I understand that doing something – anything - was the only way I could cope and feel I was helping my Mom in a situation that was beyond difficult.

I look back with love and gratitude that I was so close to Mom toward the end of her life. I loved being so physically close to her and caring about her in ways words failed me. Caregiving was a hardship and a gift that has never left me all these years later. I’ll speak for myself and Mom and say, we hope patients, caregivers, and loved ones can find practical everyday support and guidance in the Skincare Corner. Please know it’s written and put together with a great deal of love from all of us (the nurses and physicians, the staff at the CL Foundation, me and Mom) to you.