

Mr. Chairman, Committee Members, and Guests:

Thank you for allowing me the opportunity to speak to you today. As a melanoma survivor, I am a passionate advocate for the prevention of skin cancers and strongly disapprove of indoor tanning devices. For without them, I believe that I would have been spared the tragedy of battling stage III melanoma.

For many people, January 23, 2009 was just another day; for me, it is a day that I will never forget. A phone call early that morning from my dermatologist changed my life forever – a mole biopsy taken just two days prior revealed malignant melanoma. At 28 years old, I had just learned that my diagnosis was cancer. Please, let me be clear. I did not get to this point by making smart choices with regard to the health of my skin. I am as guilty as the next person for not always protecting my skin from sun exposure outdoors and I used tanning beds throughout my early 20s. I regret every minute I spent frying my skin with UV radiation.

Biologically-speaking, I am a walking risk factor for melanoma – blond hair, blue eyes, and the palest skin tone dotted with freckles and moles. As a teenager and young adult though, I never thought twice about it. Society and peer pressure said that to look “right” I needed to be tan. My family tried to warn me about the dangers of tanning, especially when I began to use tanning beds at the age of 20 but I chose to ignore them. Once I got past the initial sunburn that never failed to appear in my first few tanning sessions, I would begin to develop that golden brown glow. Looking tan was healthy, right? The more times I went tanning, the better I felt. I wanted the color to become even deeper – I never looked tan enough. Looking back at pictures of myself from that point in time however, I cannot help but criticize at how unnatural my skin appears. I went from tanning just a few times over a matter of weeks to tanning several days in a week. The salons never discouraged me from it despite my naturally pale skin – why would they? Each time I visited them they were making sales.

I am a Pennsylvania native, growing up in the small town of Bradford in McKean County. After graduating college in 2003, I moved to the Washington, DC area to attend graduate school and begin my professional career as a computer forensic investigator. Five years later, I moved to South Florida for brighter days and warmer weather. Just four months after I arrived, I noticed that a mole on the back of my left shoulder – one that had been there since birth – had started to change in appearance. It was getting larger in size, changing from a uniform brown color to red and black, and the borders were asymmetrical. Instinct told me that something was terribly wrong; reality was that I did not have health insurance so there was no possible way to have a medical professional check it out. After leaving my job in DC, I paid COBRA premiums to keep health insurance until I found new employment. What I did not anticipate was a tanking economy and rising unemployment rates. At a cost of almost \$500.00 per month and no income, I could no longer afford the COBRA premium. I was a healthy young woman with no chronic medical conditions, so I decided to drop the insurance in August of 2008.

After several months and hundreds of job applications, I was finally offered a job with health insurance benefits on my 28<sup>th</sup> birthday – October 13, 2008. I made an appointment with a primary care physician so that he could refer me to a dermatologist if necessary. The physician took a look at my worrisome mole and told me yes, it should be looked at by a dermatologist but he did not believe it was melanoma. This eased my fear somewhat, so I decided to hold off on making that appointment to have my skin checked. By December, the mole had gone from bad to worse. It was now ulcerated, cracked and bleeding, and no amount of home topical treatment would make it heal. I began to panic and called a dermatologist. She could not get me in for an appointment until mid-January of 2009.

On January 21, 2009, I finally saw the dermatologist. She took one look at the mole and said it needed to be biopsied immediately along with another mole in the middle of my back that I was completely unaware of. Two days later while making breakfast, my cell phone rang. The caller ID indicated it was my dermatologist. Deep down I knew what she was calling to tell me and I froze in fear. I let it go to voicemail while I gathered the courage to face the news I was about to hear. A few minutes later I forced myself to listen to the message – “Amy, this is Dr. Siperstein. Please call me as soon as you get this message. It is very important that I speak to you.” I took a deep breath and called her back. She had the results of my biopsies – the mole removed from the middle of my back was atypical but benign; however, the mole from my left shoulder is malignant melanoma. She went on to tell me about a surgical oncologist that she was referring me to for follow-up, but I was now in a state of shock. We hung up the phone and I went about my business. I stepped into the shower when suddenly it hit me. I thought to myself, “Did she just say I have cancer? I can’t have cancer, I am too young.” I collapsed right there in the shower, tears pouring from my eyes. “Oh my God, I have cancer.”

I had no support system in Florida – no family and only a few friends that I had just recently met. My mom, sister, and best friend flew down from Pennsylvania to be with me while the oncologist ran multiple tests to determine the extent of the melanoma. After a PET scan, CT scan, chest x-ray, blood tests, surgical excision of the primary tumor, and a sentinel node biopsy, my cancer was diagnosed as stage III melanoma. The primary tumor was 4 mm thick and the sentinel node biopsy tested positive for cancer. With these results, I made the decision to move back to Pennsylvania and live with my parents. There was no possible way I could undergo treatment while living on my own 1,500 miles away from my biggest support system. My surgical oncologist in Florida referred me to Roswell Park Cancer Institute in Buffalo, NY for ongoing treatment. Shortly after I arrived home I went back into surgery for a complete left axillary node dissection – 70 lymph nodes were removed from under my left arm, back and chest; 32 of those nodes tested positive for cancer. My diagnosis became more specific – stage III-C melanoma and was elevated to very high risk.

Following surgery, I underwent 23 radiation treatments and 12 months of immunotherapy which involved taking the drug Interferon alpha-2B. I completed the entire year-long course of Interferon, but not without significant adverse effects. I developed hyperthyroidism which triggered cardiac problems – atrial flutter and tachycardia, significant weight loss, and the loss of all my long hair. I developed psoriasis on my scalp and severe joint pain that was early onset of rheumatoid arthritis. The silver lining is that these effects were all auto-immune responses to the Interferon – a positive indication that I will survive this melanoma. I completed my treatment in July of 2010 and I am happy to report that all subsequent scans and check-ups indicate that I am cancer-free! While I celebrate my survivorship, there is also a lingering fear that at any time the cancer could come back. I fear the sun that I once worshipped and I feel anger every time I pass a tanning salon or hear that somebody is going tanning.

My body is still recovering from the 18 months of torture it had to endure. My hair is slowly growing back, my incisions have healed, and I am no longer being poked by needles every single day; however, the 5-inch scar on my left shoulder and multiple scars from incisions and drains under my left arm remain. Thanks to the high doses of radiation to my left shoulder, I actually have a permanent tan because the radiation not only killed the cancer, but it damaged my healthy skin cells too. It created thick scar tissue which makes my underarm feel like a rock and because the radiation area included some breast tissue, I am now at higher risk for developing breast cancer and must get annual mammograms at the ripe old age of 30. Removal of so many lymph nodes has put me at a lifetime risk of developing lymphedema in my left arm. I wear a medical alert bracelet because I can no longer have blood pressure, injections, or intravenous access completed on that arm. Just recently I received a

minor bite wound on my left hand from our new 4-month old boxer puppy. Under normal circumstances, it would not require a trip to the emergency room; however, because an infection could trigger the chronic swelling of lymphedema, I found myself sitting in our local immediate care facility having my hand scrubbed with an antiseptic cleanser, covered in antibiotic ointment and wrapped in ridiculous amounts of gauze for something that should have only needed a small adhesive bandage. I left with a prescription in hand for oral antibiotics as a prophylaxis for any possible infection. When I reach my one-year anniversary of completing treatment this upcoming July, I will have to undergo surgery one more time to have the medical port removed from my right chest wall.

Despite all the pain and suffering I have endured, I still thank God every day that I am alive and for giving me a second chance to use my experience as a gift to others. I have made life-changing decisions as a result of surviving cancer. I have returned to school to become a Registered Nurse and I plan to specialize in Oncology so that I may help and support future cancer patients as my nurses did for me. I use my story as a melanoma survivor to educate the public on the importance of protecting your skin and the dangers of tanning. I have spent numerous hours in my local schools to educate our children on sun safety and skin cancer prevention. I cannot change the past, but in hindsight, I wish I had never used a tanning bed. I hope I live to see the day that indoor tanning devices disappear altogether and I will advocate against them for as long as I am on this Earth and have a voice. I am in full support of House Bill 369 amending Section 6911 of Title 18 and urge you as elected representatives of this Commonwealth to pass this bill into law and spare our children from ever having to experience melanoma like I did. Thank you.

Testimony Submitted By: Amy L. Silvis  
Date: Friday, May 27, 2011