

# Invisible Disability



Living With Multiple Food Allergies,  
Eczema, Contact Dermatitis and  
Severe Gluten Intolerance

Maya Trimner

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## Living With Multiple Food Allergies, Eczema, Contact Dermatitis and Gluten Intolerance

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*For my amazing food allergy mom. I know you suffered when I suffered. Thank you for keeping me alive all these years and for fanning the flame of this project.*

*Thank you, dad for keeping watch over me at all my field trips and recitals so that I wouldn't die.*

*For my amazing Papa for scratching me and holding me when I cried.*

*For grandma who is now watching over me from wherever she is. Thank you for showing me strength I didn't know I had.*

*For my cousin, Reiner for inspiring me with your resilience.*

*For all the family and friends who looked out for me over the years and tried to understand.*

*Special thanks to Omar for your expertise and friendship.*

*Thank you, Ashley, for teaching me things every day through your strength.*

*For my allergists over the years, Dr. Platts-Mills, Dr. Alcasid-Escano, Dr. Mayer and Dr. Boxer. I will never forget you.*

*For all the doctors and angels in the ER who saved my life. I might not remember your names but I am forever grateful.*

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# Prologue

I can't remember ever having long, graceful fingers. Sometimes, I wish I did. Instead I have thickened, coarse fingers and joints with loose, wrinkled skin that remind me of a bloodhound. Sad just like that, too. As a child, I stared at my mom's hands while she scratched me and lulled me in and out of sleep, looking down at my small, swollen fingers stinging from cuts from scratching all night. The years didn't match my hands and they never would. I've felt embarrassed and ashamed of them when people I dated held them to look at them. I wanted to hide them with every chance I could. To me, they were ugly and swollen; because of them I would never be beautiful. Once people saw my hands, they would see the truth.

I would use anti-wrinkle creams on them, hoping they would diminish some of the lines, but of course they did more harm than good. Not only did they not work, but I was usually allergic to them and would end up scrubbing the cream off and settling for good old corticosteroid cream and petroleum jelly.

But then I think about the role my hands play in the bigger picture and I am so grateful. These hands connect me to my inner voice and the many ways I express myself, whether its through drawing, painting or writing. These hands have brought me to places I never thought they could take me...and that, is beautiful.

Now I look at my hands with love and compassion. Because if we don't have it for ourselves, how can we possibly have

it for anyone else? Cherishing our imperfections brings us to a new level of maturity and freedom a select group on this planet possess.

Instead of following the crowd, I've learned that standing up and embracing our differences takes courage. Like attracts like and only honesty will keep the genuine people in your circle. My hands are now an asset to me in every way and I see them as symbols of strength, not illness.

Yet if my hands could speak, they would tell my tale. Each line and indentation tells a story of a girl who triumphs above struggles very few understand. Hopefully the lines on my hands inspire you and make you appreciate all you do have in this often complicated, yet amazing journey called life.

# Compassion Challenge

I know you're reading this for the first time wondering, what is this book about?

This first chapter is for anyone who does not have a soy allergy. I'm not going to go into how lucky you are, because navigating my way through a soy-filled terrain has taught me more about food and myself than I would have ever thought possible. Even if you live with multiple allergies like I do, if your list does not include soy or corn, consider yourself one of the luckier ones. Really.

Living with soy allergy has opened my eyes to the deceptive marketing practices of companies trying to grab your last dollar and has also opened my eyes to the fact that there really are good people out there who will try to understand what you go through and accomodate you in the best way they know how.

The rest of this book is geared towards those with severe food allergies, skin sensitivities, celiac disease and severe gluten intolerance. Those of you who deal with these things on a daily basis will likely read a story that you might relate to or might have handled differently.

But for those of you who really don't believe that soy is in anything but your nearest Japanese restaurant, I dare you to take what I call, *The Compassion Challenge*.

Soy allergy affects one per cent of the population and the rate is steadily increasing. I have lived with soy allergy for almost all of my life. I've gone into anaphylactic shock from

accidentally eating tofu pureed into a salad dressing. I have to avoid soy in all its forms or else I will suffer or worse.

### **The Compassion Challenge**

Your challenge is to find one soy-free item in your nearest grocery store. Health food stores not allowed!

If you don't like to cook, find me ONE frozen dinner without soy or any soy derivatives. If you need help knowing what derivatives are soy-derived, go to the end of this chapter for *The List*.

Let's start with bread. Then prepared soup. Then cereal. Anything?

Didn't think so.

This list is not the definitive list for all soy but may be used as base point to know what to look out for and which foods and items usually or may contain soy.

#### *The List*

olive oil (may actually be unlabeled soybean oil if its from outside the USA or not USDA Organic. Th)

eggs (if you are sensitive to soybean oil, you will likely react to soy-fed chicken eggs. I react to some brands more than others because I suspect the chickens are fed soy. Stick with flaxseed-fed USDA Organic eggs to minimize this risk)

chicken (most big names on the market are soy-fed. Choose organic and call company if you're sensitive to soybean oil.)

beef (Buy grass-fed only. If you are sensitive to soybean oil or natural flavors like I am, you will likely react to soy-fed beef.)

fish(choose wild-caught ONLY. Farm-raised fish are almost always fed soy)

gum arabic

tocopherol acetate (aka vitamin E which is usually soy-derived)

bulking agent

carob

emulsifier

guar gum (usually comprised of about 10% soy protein. It is also a cousin of soybeans)

hydrolyzed vegetable protein (HVP)

lecithin/soy lecithin

miso

magnesium stearate (used in many prescription and over-the-counter medications. Call manufacturer to find out source.)

USDA Organic Milk (cows are usually fed soy, grains, peas, etc. Go for grass-fed only. If you're sensitive to soybean oil you will likely be sensitive to milk that's fed with soy)

MSG (Monosodium Glutamate)

natural flavors

protein

protein extender

soy flour

soy nuts

soy panthenol

soy protein

soy protein isolate or concentrate

soy sauce

soybean

soybean oil

stabilizer

starch

stearic acid (used as binder in vitamins, medications and in many lotions, creams, cosmetics)

textured vegetable protein (TVP)

thickener

tofu

vegetable broth

vegetable gum

vegetable starch

xanthan gum (can be derived from corn, wheat or soy)

**Hidden soy derivatives in lotions, creams, bath products, household products, lawn and auto etc....**

Vitamin E (Likely derived from soy. Call manufacturer to be sure)

PEG-10 soya sterol

glycerin (usually made from soybean oil. Call manufacturer to find out its source.)

glycerine

Soy sterol

Soy protein

Soy protein concentrate

Proteins

Soybean protein

Soy acid

Soy acid;

Acids, soy;

Fatty acids, soya

PEG-16 soy sterol

PEG-75 soy glycerides

Stearic Acid

Soybean sterol

Soy glyceride, hydrogenated

Soybean oil, maleated

PEG-5 soy sterol

Alkyd resin solution

Soya oil, phthalic anhydride, pentaerythritol polymer;

Soybean oil, polymer with pentaerythritol and phthalic anhydride;

1,2-Benzenedicarboxylic anhydride, pentaerythritol, soybean oil

polymer;

Pentaerythritol, phthalic anhydride, soybean oil polymer

Soy protein, hydrolyzed

Hydrolyzed soy protein;

Soy protein, hydrolyzed;

Protein hydrolyzates, soya  
Quaternary ammonium salts  
Quaternary ammonium compounds, ethyldimethylsoya alkyl,  
Et  
Soyethyldimonium ethosulfate;  
Dimethylethylsoyaammonium ethosulfate  
Vegetable Oil  
Lecithin  
Lecithins  
Lecithine  
Soybean lecithin  
Soybean oil blend  
Soybean oil  
Extract of soy  
Oils, soybean;  
Soy germ extract;  
Soya oil;  
Soybean Oil [USAN]  
Alkyd resin  
Linseed oil, polymer with pentaerythritol, phthalic anhydride,  
oil, styrene and vinyltoluene  
Soybean meal  
Soyaethyl morpholinium ethosulfate

Morpholinium compounds  
N-ethyl-N-soya alkyl  
ethyl sulfates  
N-Soya-N-ethyl morpholinium ethosulfate  
Soyatrimonium chloride  
N-(Soya alkyl)-N,N,N-trimethyl ammonium chloride  
Quaternary ammonium compounds  
trimethylsoya  
alkyl chlorides  
Quaternium-9  
Soya trimethyl ammonium chloride

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*Exhausted, yet?* Yeah, me too. And that is only the soy derivative list. I'm also anaphylactic to peanuts and Brazil nuts. But that's not all; I'm severely allergic to lentils, chickpeas, green peas and guar gum. I have a mild dairy allergy and am severely gluten-intolerant; I have the same symptoms of Celiac Disease patients. I have environmental allergies to pollens, ragweed, dust and mold. I'm also severely allergic to liquid silicone derivatives like dimethicone as well as lavender and wool. How am I alive?

Step into my world.