

# HEAD TO HEAD

A DOCUMENTARY FILM DETANGLING IDENTITY, HEALTH, AND BEAUTY

## WOMEN'S RESOURCE GUIDE

Wigs	1
Eyebrows, Lashes, Skin	6
Insurance	9
Coping and Support	11

---

### WIGS

**Q:** *What questions do you feel are most important to ask when searching for a wig?*

**Katy:**

What are the pros and cons of synthetic vs human hair?

**Barbie:**

Along with knowing the differences between synthetic and human hair, also know the differences between heat safe synthetic, regular synthetic and synthetic/human hair blends.

**Kali:**

Fabrication: What cap and hair options do you have available?

Color/Shade/Lengths: What colors, shades and lengths do you have available?

Price: What is the price range for the wigs?

Service: Do you offer or make referrals for cutting and styling wigs that you sell?

**Margot:**

Is the hair remy? (meaning higher quality and not prone to tangling). Consider the internal mechanisms and material. The wig may be gorgeous, but it should also fit well and be relatively comfortable if possible. If you are getting one wig, consider the longevity. How long will you want/need to wear it? If you plan to wear it most of the time, is it suitable for daily activities? Can you apply heat to it, or style it easily if need be?

**Andrea**

What are your needs? How often do you plan to wear it? How much work and upkeep are you willing to do? What are you going to be doing while wearing it (physical activities, etc.)?

***Q: Where did you begin your search when you first started looking for wigs?*****Barbie:**

I went to a salon that carried wigs. I wanted to see them, feel them, try them on personally.

**Jillian:**

My first venture to a wig shop was a nightmare experience... I don't remember what the place was called but hopefully it's out of business. My first human hair wig was from J. Crager Alternatives, my second was from Hair Response, and then I finally found my favorite 3rd and 4th wigs online.

**Leah:**

The first wig store I saw was in a "nice" area over 20 years ago. There was no ethnic representation in hair styles or assistance along the way.

**Margot:**

I first looked for free wigs at local non-profit organizations. Though the organizations were great, that did not end successfully for me as there weren't any options in style or color for a person my age. I then looked to custom wig stylists in my area. The wigs offered from these companies were high quality and designed to look very natural, but were often pricy, between \$1k - \$4k. Companies like these often work with insurance.

Finally, my only real option was beauty supply wigs, which I think have increased dramatically in quality since 2010. There are typically many, many options for quality, material (synthetic or human), style, price, etc. Depending on all of these factors, costs can range from \$30 to \$500. But these wigs are not really made for individuals with total hair loss, so they may not be the most comfortable option, but if time or price is a factor, they are a good option.

There are many options for wigs online of similar quality and construction to beauty supply wigs, but they may cost more depending on the supplier. My suggestion is to stay away from alibaba.com and keep in mind that most wigs you come across, anywhere, are non-refundable.

**Andrea:**

I started wearing wigs when I was 14, so my mom was doing most of the research for me. From what I can remember, we started with a woman who had a non-profit that offered wigs for kids with cancer. Then after that I think my mom found a hairdresser at her salon who also did wigs. And I stuck with her for at least a decade. This was all in Ohio.

***Q: What was the biggest lesson you learned along the way? (And are perhaps still learning?)***

**Barbie:**

Just because you have purchased a particular wig before, does not mean it will look, fit or feel the same way as the previous one. Even if you keep with the exact same company, product and color; no two wigs are the same. Also, wigs stretch with time, wear and washing. At some point it will feel bulky. Not necessarily loose around the rim, but the dome part will have extra space.

**Jillian:**

Self-acceptance starts from within.

**Leah:**

If it's NOT what you want, then walk away from it and keep looking!

**Andrea:**

You don't need to choose between always wearing a wig, or never wearing one. People in your life may be much more understanding than you give them credit for. Also, that cashier at the pharmacy is probably not going to remember you if you wear a wig one week, and not wear one the next.

**Stacey:**

I stopped wearing a wig to make my family members comfortable. The wig I had felt itchy and most importantly didn't feel like ME. So, one day I decided to stop wearing it altogether. The lesson for me was to do what made me feel authentic. For you it may be to wear a wig. This is about making the right choice for YOU, rather than to please others.

***Q: Where do you look now when you are purchasing a new wig? Do you find any suppliers to be particularly helpful? What resources do you find particularly helpful/reliable when looking for a hair supplier?***

**Barbie:**

I found Loris wig site (<https://www.wigsite.com>) at the [National Alopecia Areata Foundation |www.naaf.org](http://www.naaf.org) web page. I discovered a "medical wigs" section and found one that has worked pretty well for me for a few years. Silicone is a must for me. I am always open to and on the lookout for an even better wig. On a side note, if a wig lining becomes old and scratchy or you just need help with sweat collecting on your scalp under a wig, try [Headline It!](#)

**Jillian:**

[www.gardeauxwigs.com](http://www.gardeauxwigs.com)

**Leah:**

I look wherever they have hair to sell as wigs, which usually means they have loose hair and partial pieces, too.

**Q: What advice do you have for someone who is looking for a wig for the first or second time?**

**Barbie:**

If possible, find a place that has a private area where you can try wigs on first. Don't spend a fortune at first. Give yourself time to discover what works for you and what doesn't before spending a lot.. For instance, skin reactions to the interior fabrics may occur. Do you prefer velcro or hook adjustments? Do you know what size you wear? How long do certain fibers or hair qualities last for your lifestyle? The last thing you want is to be stuck with an expensive wig that is uncomfortable or falls apart quickly. Try to stick with reputable brands. Read reviews on the company and actual wigs if possible. Don't get discouraged, you will find one that suits you.

**Jillian:**

Bring photos of what you're hoping to find. Don't let someone convince you that the wig looks nice on you unless YOU feel confident and comfortable in it.

**Leah:**

You should look for a texture of hair that reflects *your* distinct style. Some styles work best with certain textures. If you *think* you'll like something, but don't feel compelled to "represent," it's okay to recognize that *you* are the one who has to feel comfortable in it all day, every day. Plus, the times are better. The supply is distinctly more varied and the texture, length, style, and even the color of your 'do is completely up to you! Don't see it? Have it made! Loose hair is a booming market. There are tutorials for anyone who is inclined.

**Kali:**

Most wigs are designed to be custom cut and styled on/for the client. They are manufactured with 30-50 more hair than what ultimately is needed for the best look. So even if you like a wig and style - you will like it more once it is custom cut to your face and head! Also an important thing to note - Cap fabrication is critically linked to fit and comfort.

When possible, start looking early so you can take your time. You may have to kiss a few frogs before you find the perfect wig for you! I often suggest purchasing less expensive synthetic wig(s) first to try out the look/style, then upgrading to human hair and custom fabrication if desired.

**Andrea:**

Starting out with synthetic was definitely the right choice for me (especially as a young teen). Work your way up to real hair if that makes sense to you. Also, good quality human hair shouldn't get tangled up after 2 or 3 washes. If it does, you need to make sure you are actually getting remy hair. I spent too many years with wigs that had sub-par hair, and didn't realize that it wasn't how things were supposed to be.

***Q: Any other questions you want to ask/answer about wigs?***

**Barbie:**

When trying to find comfort in regards to a totally bald head ( Alopecia universalis/totalis), wig selection is more limited in my opinion. Keywords to look for are: Medical wigs, Cranial prosthesis, silicone/silicone lining, thin skin lining.

**Leah:**

Check in with your wig wearing Girlz!

## EYEBROWS, LASHES, AND SKIN

***Q: Where did you find information about eyebrow, lash, skin rash/scarring solutions?***

**Barbie:**

Youtube tutorials, Facebook groups and alopecia pages, National Alopecia Areata Foundation website, [Bald Girls Do Lunch](#) website.

**Leah:**

Dr Jolly's second self-esteem affirmation workshop. We learned about products that can conceal lesions. And how to use makeup for desired effects. But even more, we learned that we're ENOUGH no matter what else we are.

**Pamela:**

Research, Lupus Foundation of America, online groups, talking with people who also have Lupus.

***Q: What have you tried? What have you wanted to try?***

**Barbie:**

I have tried hundreds of over the counter and speciality website makeup products (powders, shadows, eye liners, brow kits, brow dyes, stencils, stamps, removable tattoos, false eyelashes, real hair eyelashes, real hair eyebrows, magnetic eyelashes, powder brows with digital tattoo needling.

**Leah:**

I'd like to get my eyebrows tattooed back on. Drawing them is ok but it would be nice not to worry if they're straight, match, or wiped off - especially since they're not coming back.

**Pamela:**

For eyebrows, I've wanted to try brow tattooing but that is not an option when you have Lupus. I did find a great alternative, "Brow Tinting". Skin rash/scarring can improve over time but some scarring will remain depending on the individual and severity of the scarring. Seeing a Dermatologist is also recommended. Ointments and creams help with itching but mostly medication prescribed by my Rheumatologist helps to keep the Lupus in remission. Makeup works great for facial scarring or discoloration.

***Q: What has worked best for you?***

**Barbie:**

I was not a good candidate for Microblading brows. I was better suited for a technique combination of powder brow (shading of color) and digital tattoo needling (hair strokes).

(<https://www.microcosmetic.com>)

**Pamela:**

For keeping the Lupus in remission, prescribed medication, Imuran, has worked best for me. Regular visits to my Rheumatologist for examination and talking to discuss current and future treatments and getting blood work done regularly.

**Stacey:**

I have learned to keep my stress under control. This has often required saying “no” to attending events when I am tired, and “no” to friendships that are toxic. It has required that I prioritize my health above pleasing others, those who love me always understand when I am in pain or tired. Science is finding that emotional pain is perceived by the body just as physical pain, and I have found this to be true- in times of depression my physical pain from lupus has felt worse. Thus, I seek support when I am feeling down, I speak to my therapist, I take my antidepressants.

***Q: What has not worked well, and why?*****Barbie:**

For me, Over the counter makeup that isn't waterproof didn't work well. They wear off, wipe off and sweat off too easily. I was reapplying many times throughout the day therefore using products faster and costing more money.

**Leah:**

Heavy makeup in hot weather.

**Pamela:**

Plaquenil worked well for many years but recently attributed to muscle weakness in my legs.

**Stacey:**

It has not worked well for me to isolate myself when I am feeling down or experiencing a lupus flare. Although sometimes I do not have the energy, I do choose to spend time with my loved ones because at the end of the day this brings joy to my life. It's sort of a balancing act of learning not to push my body over the cliff but also not allowing my disease to restrict me completely from doing the things I enjoy.

***Q: Do you have any specific makeup and/or application recommendations?*****Barbie:**

[Bald Girls Do Lunch](#) has a brow line of products that work and last. BGDL Brow Powder, BG Brow Sealer, Dollywink and Eyescream eyeliner.

**Leah:**

Kiss Cover Cream (I mix 2 for stellar color match results). Also, while more costly, is Dermablend which I find at some department stores.

**Pamela:**

I have tried quite a few different makeup brands. Right now I'm using IL Makiage, a brand I saw advertised and so far it's working well, I use a brush for application. You get full size bottles to try before buying it, if it's not what you want you can return it, no hassles. They have the best Customer Support I have dealt with in years. You just have to try different brands and know your skin type, oily, dry, mixed and what shade matches your skin tone. I have also found watching tutorials on YouTube to be very useful.

**Q: *What has been your greatest challenge? Your greatest success?*****Barbie:**

Brow shape, shade and color have always been difficult, frustrating and most time consuming for me. Your greatest success? Barbie: Taking the leap after much hesitation to get permanent make up done. I have so much more time and less frustration.

**Leah:**

Learning to relax about the perceptions of others toward me. Being lovely to myself, and walking in *that*.

**Pamela:**

My greatest challenge was accepting and adjusting to a new lifestyle. Not being able to dress the way I would like, embarrassed by my body, scarring, dating and not being comfortable in my own skin. My greatest success has been acceptance and learning to be happy. I have found clothes, always long sleeves and pants due to scarring, that enhance what I cannot expose that look good on my body type. I have learned how to use makeup for covering dark spots on my face. I have discovered the positive, proud side of myself again.

**Stacey:**

My greatest challenge has been accepting my physical limitations and all that comes with it- change in appearance, taking tons of medications daily, seeing so many specialists for my care, and having to make all my plans with the understanding that having lupus restricts major life choices. For example, being immunocompromised means I cannot attend large events. Family planning entails understanding my pregnancy will automatically be regarded as "high-risk" and all the extra tests and increased anxiety that comes with that title. My greatest success is I am still pushing forward with my professional and personal goals. My journey has not followed a conventional road, but I am on my way to becoming a physician and a mother within the next few months!

## INSURANCE

***Q: Have you tried to get wigs covered by insurance? Did it work?***

**Barbie:**

Several years ago I did try and never did get a straight answer from them. I gave up quickly. Back then it was rare to even ask for coverage of a wig.

**Margot:**

After my breast cancer diagnosis, I tried pretty much non-stop for a few weeks, hoping to attain coverage before my hair fell out. But I was met with barriers at every step. Whether it was a denial from “lack of submitting the proper medical codes”, or the fact that I didn’t have the “correct” diagnosis to qualify, it left me deflated and exhausted. Given that my situation was temporary, once my hair fell out, I decided to purchase one out of pocket instead, and I never tried again.

**Andrea:**

No. However, I think there are still some resources for young people under 18 to get their wigs for free from a non-profit organization. Not just for cancer, but for alopecia or any kind of medically induced hair loss.

***Q: Have you heard of anyone getting coverage? In full or in part?***

**Barbie:**

Personally, no, I don't know of anyone getting coverage.

**Leah:**

No.

**Andrea:**

Not through insurance, no.

**Margot:**

I have since heard of cranial prosthetics being covered partially or in full from a few individuals with cancer, so apparently it is not impossible, but if you were to try, I would fully expect to jump through hoops.

***Q: How would you recommend approaching insurance companies if someone is looking to obtain coverage?***

**Margot:**

I can't really recommend it as it seems they are seldom covered, but maybe if you have some extra energy, and are prepared for rejection, go for it, you might as well give it a shot.

***Q: What are some of the pitfalls to avoid?***

**Margot:**

From what I understand, cranial prosthetics may often be covered but only partially, so if you are lucky enough to obtain coverage, make sure you know how much coverage you have before moving forward with any part of purchasing the wig and submitting reimbursement. Wigs can be extremely pricy, and the last thing you want is to think a \$2k wig is covered, but it's only 10%.

***Q: What are some loopholes in the system, if any?***

**Leah:**

I think you still have to fudge your ailment to fit listed parameters. Our stuff is rarely covered without adding big league issues that are life threatening, and common to Caucasian people, too.

## COPING AND SUPPORT

### ***Q: What groups have you joined for support and solidarity?***

#### **Barbie:**

Aside from social media groups or pages, I have not attended any physical support groups.

#### **Jillian:**

I started looking at the #alopecia hashtags on Instagram and quickly found a lot of women my age, who were open online about their hair loss. Just following them on social media helped me feel like I found my hairloss village when I was in the early days.

#### **Leah:**

[MyLupusTeam.com](http://MyLupusTeam.com). A great bunch of "girls like me" who help each other through daily things.

#### **Stacey:**

I have joined a Lupus Support Group at Rush. I have also found that people with other chronic illnesses can relate to many of the challenges I have faced, so people do not need to have the same physical illness to form strong connections.

### ***Q: What can a family member or friend do to support you or someone experiencing hair loss?***

#### **Barbie:**

Listen without too much advice. Most of the time I just wanted my fears, insecurities and frustrations heard when the people around me could not really relate to my issues. Encourage discussions of ways to navigate said issues and what could be considered a "doable approach" or an "undoable approach". Most importantly, just be there. Doing things in public as a vulnerable alopecian can be debilitating. Having a loved one that knows you, can be honest with you and has your back when you get "the looks" or comments of the public is more valuable than I can express.

#### **Jillian:**

Please ask them to not send hair loss infomercials your way thinking the product they're selling will help (thanks, Dad -\_-). Ask someone to tag along with you to your first wig shopping experience, listen and lend a shoulder to cry on.

#### **Leah:**

Go hair shopping with them ... and tell them the truth! Experiment with other hair coverings. Scarves, turbans, caps etc.

#### **Andrea:**

I always want honest feedback from people about my wig. Just telling me "you look great", is not all that helpful to me.

**Stacey:**

I think this is very unique to each person who is facing hair loss. It helped me when my friends and family members normalized my change in appearance. They respected my decision to wear or not wear a wig. I think it is also helpful to be asked directly "how can I support you?" rather than make assumptions.

***Q: If someone can take away one thing from your life experiences, what would you want them to know or learn?***

**Barbie:**

Be patient with yourself and the journey. You will hear all kinds of advice. You will see all spectrums of behavior from other folx with hair loss ranging from bold/brave to withdrawn/depressed. There isn't a correct path. There isn't a perfect timeline. One method does not fit all. Don't feel guilty when your journey doesn't look like another. You are the only one that has to live your life with hairloss. Be genuine in your journey and always strive for acceptance and good mental health.

**Jillian:**

You WILL feel like yourself again. You'll just be a stronger, better version of yourself :)

**Leah:**

Everything is fluid. You have to be in this body from now on. You *must* prioritize your comfort and ability. You have to recognize what you can do for yourself to comfort your psyche. Be your own standard of beauty. No one else can do it as well as you.

**Andrea:**

Feeling acceptance from others is not the same as acceptance from yourself. If you don't accept yourself, no one else is really going to make you feel better.

**Stacey:**

I would want people to learn that every challenge is an opportunity for growth. When we view things with this perspective, it becomes easier to hang on during difficult times and look forward to using our experience to benefit others. I think it's also important to recognize that your illness affects those who love you significantly, allow them to cope in the ways they need and be patient when they don't understand what you're going through. Learn to communicate your needs to your loved ones and learn to be an advocate for yourself when you receive care in the hospital/clinic setting.

***Q: What kinds of activities help you cope when you're facing rough days?***

**Barbie:**

It helps me to read Facebook Alopecia group posts and comments. It also helps me remember I am not alone. So many of their grievances are or have been mine as well. The supportive comments from strangers that have been through similar rough days can be very therapeutic for me.

**Jillian:**

Running helped me gain my confidence back. It also helped me find inner peace and is my go-to on a rough or regular day.

**Leah:**

Art & music. Loved ones caring however they do.

**Andrea:**

It's crucial for me to do something outside myself. Too much self reflection can be really draining, and not necessarily be healthy.

**Stacey:**

I turn to prayer, journaling, speaking to a friend, exercising, long baths, and getting outdoors.

***Q: What kinds of activities keep your spirits up?***

**Barbie:**

Typically I spend time with or reach out to close friends that won't judge me. Sometimes just talking it out with a friend and moving on to a fun activity with them is a day saver.

**Leah:**

Drawing. Creating basically anything. Cooking, too. I love and recently published a new young adult book about Lupus as portrayed through the eyes of a young girl, titled [\*Lucy Lupus of Trista Lee\*](#).

**Stacey:**

Spending time with my loved ones and serving others in my workplace or through volunteer work.

**Q: What are some of your favorite accounts/people you follow on social media, or out in the community, that other people should keep tabs on?**

**Barbie:**

National Alopecia Areata Foundation: <https://www.naaf.org>

Bald Girls Do Lunch: <https://www.baldgirlsdoalunch.org>

Ebony Jean youtube tutorials <https://youtu.be/mRjdaWoprdM>

Joelle youtube tutorials <https://youtu.be/P3hzM-DBahI>

Children's Alopecia Project <https://www.childrensalopeciaproject.org>

Facebook Alopecia Universalis Support [Alopecia Universalis Support Group](#)

Facebook Alopecia Totalis and Universalis Support [Alopecia Totalis and Universalis Support](#)

**Stacey:**

I would encourage people to support the cause by posting on social media about lupus, sharing posts from the Lupus Society of Illinois, and the Lupus Foundation of America.

---

**[Facebook](#)**

**[Instagram](#)**

**[Contact Us](#)**