BALD GIRLS DO LUNCH

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Public Meeting of Patient-Focused Drug Development for Alopecia Areata

Organization Submission:
Bald Girls Do Lunch (501c3) nonprofit for females with Alopecia Areata
Comments Collated by Thea D. Chassin, CEO, Scarborough, NY

Following are the verbatim written submissions of 30 individuals in the Bald Girls Do Lunch nonprofit's community between November 11 and November 13, 2017.

Mary Cavallero, New York

1.The most significant symptom is my loss of eyebrows. I can leave my house with a bald head, but without applying some sort of eyebrow powder or temporary tattoo eyebrows, I look very sick & so unnatural. It's not easy applying makieup or tattoos. When you get it wrong (uneven eyebrows etc) you have to start all over again. This adds a lot of time to the morning routine of getting ready for work.

2. As a 65 year old with a loving husband who is not concerned about my looks, I have not felt that there's nothing I can't do. However, this was not the case at the start of my alopecia when I wondered how could I go swimming or go to a wedding or other event when I did not want to draw attention to myself as a bald woman. I eventually bought a Freedom wig for a lot of money - $3000. The cheaper wig I had bought was uncomfortable, but even this expensive wig is hot when it's warm.
3. When I was first diagosed, I went to bed crying & woke up crying. Looking at a person in the mirror ,whom I did not recognize was so difficult. I had always receeived compliments on my hair. I saw a pyschologist who explained that I was having an identity problem & she helped me to deal with that.

3. Best days - I have learned how to wear head scarves thanks to Bald Girls do Lunch & that it's good to wear matching earrings - those days I get compliments on my appearance. Worst days - there are many moments with bad experiences ' Like being in Sam's Club when a child tells his gramdma -"Look that lady doesn't have hair." while the grandma is trying to shush the child. On some days, i have the strength to explain to that family what my situation is - on other days, I try to ignore the comments or the stares. Sometimes I suspect people think I may be from the Middle East because I'm weating a head scarf .
4. Currently, my scalp hair is beginning to grow back. I'm going for ILK shots in my scalp & eyebrows (ouch) & twice a week Excimer Lazer treatments & I'm using Dithrocream 1% every day for 45 minutes.

5. I know I'm liklely to loose my hair again.

G.S. New York

Health Effects and Daily impacts

1.Being bald over entire body for from 2015.
Depression.
2. Avoiding social setings gatherings/ sports/
3. Depression, starts by looking in the mirror in mornings.
4.No.
5.That I get more auto immune ailments like Chrons, Diabetes, ETC

Approaches to Treatment

1. Prednisone (experimental) therapy
2 not well
3 depression, high risk side effects.
4 a safe cure/ therapy without long term dangerous side effects as much as possible.
Like Stemcel educator therapy

Catherine M. Holcomb, South Dakota

I like swimming. Hard to do wearing a wig. My husband has asked me to do certain activities with him while vacationing and I have to say "No...my hair. My point is, this not only affects me, but my family as well. Weather conditions bother me, to hot, to windy. Please come up with a cure or at least have insurance companies allow enough money to pay for a good hairpiece that suctions to your head. They're out there to purchase. I had one when I could afford it. Since I've retired I can't afford the $2500-$3000 purchase. Please help us!

Anonymous, Arizona

I have n current treatment that works. My life has been negatively affected I so many was from boyfriends dumping me to jobs being denied to me to harassment in the workplace t humiliation in public to suicidal thoughts to escape the very real n

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Anonymous, New York

I am universally bald for more than 14 years...... I can no longer partake in water activities like I used to .. swim, scuba, etc, as the bathing cap does not stay on that well. will not go au natural either...
Wearing the wig, is like wearing a bathing cap, especially in the summer, when its hot and humid. I perspire like crazy and the sweat just drips down the side of my face like a faucet, which is embarrassing.
Human Wig plans are very expensive and not covered under insurance at all. I want my hair to look as human and natural as possible, especially in the work field I am in.
sure wish there was a cure.
I have been in studies before losing it all and had no luck with regrowth.

Mary H. Mack, Michigan

Health affects and daily impacts:

1. The symptoms with the most impact on my life has been total hair loss, especially scalp hair, eyebrows, eyelashes and nose hair. Without eyebrow or eyelash hair, I have had to take extra time and effort each morning to painstakingly apply finely drawn eyebrows and eye make up. Without nose hair, it is impossible to feel when your nose is leaking until it drips out.

2. I no longer swim anymore or use health club or hotel facilities like saunas or hot tubs for fear of dislodging or damaging my wig.

3. On the worst days (weekdays on my job), I experience the constant ridicule and humiliation inflicted on me by my middle school students who find it an easy target for expressing their contempt and disrespect. Every year there are a number of students who make my teaching life hell. For example, I no longer walk down the school stairs with students because there inevitably will be some boy who would try to snatch off my wig from behind or throw some paper in my hair which I cannot feel through my wig. On the best days (on the weekends when I am not at work) it is merely an inconvenience.
4) My condition slightly improved over time. I regained a little eyelash, eyebrow and nose hair, which has made my morning make-up routine much easier and improved my appearance.
I define my condition today as being well-managed. I purchase a new wig every year.

5. I have no worries.

Perspectives on approaches to treatment:

1. I am not currently treating my condition except to apply make-up and a wig.

2. I am currently doing nothing to control my condition. In the past, I have tried cortisone injections at first, then tar and other caustic treatments. Nothing stopped the progression or reversed the condition of my alopecia universalis, and some treatments were painful and very messy. A recent dermatology appointment could not informa me with of any new treatments.

3. Currently, the most significant downside is the expense of a wig, which is not covered by my insurance. Each year I spend about $1200 to purchase a new one, since they do not last beyond that.

4. The most meaningful improvement a treatment could provide would be to restore scalp hair, or at least enough to be able to use hair woven onto my own.

The only factors affecting selection of a course of treatment would be cost and side effects (if a medication).

Kendal Ferguson, Virginia

My comment is specifically for #4 under “patient perspective on current treatment”. Unless there is a potential drug that will allow me to regain my hair, I think a meaningful treatment would be prescribing quality wigs. This treatment needs to be looked at as just that, a treatment. Not a cosmetic option.

As for what I take into consideration is how any treatment will impact my overall physical health. The only treatment options I’ve had so far have had great health risks to include any and all negative side-effects associated with steroid injections and immune effects from oral remedies. Basically, I don’t want to put myself at higher risk for cancer in order to maintain my mental health.

Ronda Dysart, Missouri

4. I have accepted me for who I am without hair. I am still me no matter what.
5. Nothing really worries me about my condition. I can't change things I know who I am in my own skin. I am very thankful for my life and my family who is with me along the way.

I am not doing treatment at this time. I have done the steriod shots which didnt help so I have to decided I am going along for the ride. And what ever happens I can deal with it cause I have alot of things I am grateful for. I think this makes me a stronger person to deal with whatever comes my way. Thanks for letting me share my view on Alopecia. I have Alopecia Totalis. I have had it for 9 years.

Angela Evans, Pennsylvania

Alopecia Universalis has been a nightmare. It impacts your self-esteem. Fortunately I was able to buy a decent wig but my heart goes out to those who cannot afford one. The insurance company would not pay. One Dr. wanted me to use an acid which could burn my head and cause scarring. I decided against that treatment. I gave up on the medical model. I turned to God and prayer and essential nutrients. My hair has now returned in all areas on my body. Thank God.

Anonymous, state unknown

Having this condition as a 20 year old is hard. I am scared that I will not be taken seriously at work, and in my future career possibilities.

Karen Sellers, California

Health Effects and Daily Impacts

1..1. Looking in mirrors.

2. Watching TV or being in public and noticing hair and relaasing I do not have any.

3. Goingin to bed with my boyfriend with a scarf or had beacuse I do not want him to see my head.

2. 1. Go to the beach - I live 1/2 a mile away. Go camping the smoke get in my wigs. Have people hug me and think my wig might fall off.

3. Every day being self conscious and never stop adjusthing my wig and always think every body is looking at me.

4. My condition started over 20 years ago but at that time the spots were the size of quarters and I could hid them. Now I have not hair and I have given up. I am not doing any treatments now. Nothing worked and I have given up. It is very depressing and I am now taking antidepressants.

5. Probably the fact that I will never have hair again and will ware a wig for the rest of my life.

Perspectives on Approaches to Treatment

1. Nothing - nothing works.

2. N/a

3. I tried shots and got 30 every other week for almost 2 years. They worked for a while and my hair was coming back then it all fell out. I also tried DNCB it was so severe I could not ware a wig.

4. The ideal treatment would work. I would try anything.

. Getting my hair back

. If it works and how long it might take to work and if the cure is not worse then the condition.

The only thing I did not do was take Prednisone by orally. That was to drastic.

Anonymous, New Hampshire

Loosing all hair is devastating and no wig or cute hat can make up for that. I dont participate in as many outdoor activities and sports as I used to due to my alopecia. There is currently no treatment but having hair back would be absolutely amazing! There could be a treatment if there was enough money allocated for research! Being bald is devastating and has a huge impact on lifestyle and self esteeem.

Maryann French, Pennsylvania

I have alopecia totalis and am not treating it or looking for a cure. I simply wish that more people were aware of the condition and could understand that women lose their hair, for reasons besides chemo treatments. I choose to not wear a wig and am often questioned about my appearance. Most of the people I speak to about my lack of hair either have alopecia themselves or know someone else with it. My hope is that someday, women who are bald (for whatever reason) won't be seen as strange and won't feel the need to hide behind wigs or subject themselves to unneeded medical treatments.

Maryann Powers, New Jersey

Total hair loss, people look at you differently. The first question usually is what type of cancer do you have..

Lao insurance companies will not pay for a cranial hair prostatic if you have Alopecia, but they will pay if you have cancer. Strange people when done with chemo will regrow hair. I have Alopecia universalis, my hair is not growing back

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Anonymous, New Jersey

Since my alopecia began my self esteem is non-existence. I have no confidence and very self conceice of my condition. Although it's not a life treating condition hair lost especially for women like in cancer patience while loosing hair during their chimo feel less of themselves.
I've been on Zoloft since 2001 because of my alopecia. I do not swim or exercise because wearing a wig is not possible for these activities. I wake up everyday depressed knowing the wig needs to go on before I start my day.
I've tried all treatments in the market since the beginning and in reality there is nothing out there that works. I've had cortisone injections into my scalp, I've taken hair grow meds, I seen all the top demotogist in NYC/NJ and they all say the same thing. It might be stress or hormones related and there is nothing they can do...I each end out to Columbia Pesbetirean for a study they where conducting a couple of years ago but never heard.
Very frustrated and disillusioned

Anonymous, Australia

1. I believe my symptoms first appeared with change of life and a traumatic death in family. no eyebrows, no eyelashes and no hair on head (can deal with no hair everywhere else)
2. going swimming with a group of people and I would be the only bald girl

3. I dont participate if feeling uncomfortable b/c I freeze inside. I struggle with exercise in summer b/c I over heat and need to take my wig off - if too many people I wont do this so just dont participate.
4. I have had the condition for 2 1/2 years and am now 56 - I focus on managing my thinking, being kind to myself, surrounding myself only with people who are supportive and I feel safe with (the rest I keep at arms distance - this includes unsupportive family). As I have confronted myself I am less worried about taking wig off when doing exercise etc...
5. People starring at me.
1. Nothing b/c nothing will cure me from the condition. there currently is no cure. All the rest give false hope which I think is even worse.
2. It doesnt
3. Treatments I tried irrated my skin - skin has become more sensitive. Gave false hope which I believe to be worse for ones state of mind. May as well deal with the situation and learn not to be attached to what used to be (Buddhist philosophy)
5. A cure that works and is truthful. A meaningful treatment is for hair to grow back all over the way it was - not whispy and sick looking.
I would only take on a treatment that had a very high success rate. Some treatments in saying the above could be teaching people how to create new trends e.g. tying scarves, turbans, how to do sport and keep head covered but look trendy without looking like you have cancer.
In addition - my family is quite interesting as my mum has dieabetes (during pregnancy and then late onset which I believe to be during change of life); One of mum's sisters has same thing. My Mum has also developed parkinsons (late life); my middle sister has got MS (Late life); I got Alopecia (late life and more chronic after 14 yr old nephew suicided) and Gum disease (late life); Cousin on Mum's side got rheumatoid arthritis (late life) but her mum got nothing autoimmune.
All this runs in my mothers side of the family - unfortunately nobody talked about illness in the family but my grandfather was always worried about getting diabetes b/c his grandmother died from it. this is only what I know about but it seems Autoimmune runs in the family and in our cases comes on around menopause/later in life.
By the way I am White European descent Australian - my husband is Singaporean

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Pamela Russell, Kansas

I Hate this. I started 10 years ago. Growing my hair back 4 times. Wigs are terrible to wear. Summertime is hell. You try wearing a socking cap on all day. Your head gets so hot, with sweat running off your head. Talk about affecting your life. All your friends and family just want to fix you. Treatments, nothing works. I've tried the most horrible potions and lotions, expensive light caps. I have a swimming pool with grand kids here. I'm not that girl that can go outside balded, so you have to wear bandana on your head while you swim. I'm 62 now. I know we have Meds in market treating other illness that will work for is. Just sad to think its takes so very long to get them though FDA. Ill be dead before Government approves anything

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Anonymous, Colorado

1. No eyebrows, no eyelashes. No hair on head.

2. Swimming, roller coasters.

3. Each day I have to be brave and look in the mirror and say I look ok and life is to short o need to get out there and live it regardless.

4. I had a beautiful, thick, enviable head of hair until. I lost it all within three months after turning 40. Before that I had one patch on the back of my head about the size of a 50 cent piece. I had that at the age of about 29. It went away and I had some thinning on the sides but not enough to be to worried about. My condition is not well managed. I just live with it.

5. I worry that my daughter's and son and my grandkids may get it.

1. I am currently not doing anything for my condition. I had an injection that swelled up my forehead and did nothing for regrowth. I have battled severe psoriasis since I was a teenager and put myself through the ringer trying to deal with that condition. I researched the results of treatment for alopecia and decided I did mot want to put myself through the emotional rollercoaster with this condition as well.

2. N/A

3. N/A

4. Not harmful to my body. Ease of use.

Meaningful improvement would be regrowth over entire head without patches of bald. Eyebrow and eyelash regrowth would be the most helpful. I take into account the effectiveness and success rate as well as the side effects and emotional impact.

Susan Kukulka, Pennsylvania

My condition changed from alopecia areata to totalis and I really wish that I still had eyebrows and eyelashes the most. My grandchildren don't understand because they're very little but they have excepted me for me. I have been looked over for jobs in my career because of this condition

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Bonnie Simpkins, Maryland

No hair. Going to crowded places. Both day is not having hair eyebrows or eye lashes. There has been no changes. I can get no answers as to why this has happened, and I insurance does not cover you to get wigs. Cancer people get wigs and their hair grows back. Mine will not??? I am told there is no treatment. Again what treatment is there other than wearing a wig which I have to pay for myself. This is a disease as you have stated. Insurance covers nothing for this DISEASE!!

Alysha Huber, South Dakota

The only activity that I cannot participate in because of my condition is swimming. Yes, I am able to get into the pool and flutter a bit but I am not able to fully submerge because I choose to not ever go without my wig so I can't get the cap of my wig wet.
I have have not tried a treatment regimen for 28 years because none of the ones I tried as a child worked and it was emotionally draining to get my hopes up thinking that my hair would grow back and being proven wrong. However, with that said, I do NOT feel that hair follicles die because I hadn't had hair on my head for over 10 years and out of nowhere, I have a patch of hair that's growing and continues to get bigger.

Shirley Splaine, New Hampshire

I actually don't do anything about my alopecia except to look as well as I can. I've had it for Many years, am 92 yrs. old and look much younger. I'm a happy healthy person and feel I could have lost something far more devasting than hair such as eyesight or a limb. I live a very busy life and just can't worry about hair loss. I will be glad for everyone when a solution is finally found

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Donna Xander, Virginia

It's frustrating to be losing my hair. I've been to numerous doctors. Some have offered possible treatments that didn't work at all. Some offered no hope. One said, "Face it, hair just wasn't meant to be your thing." I've been depressed, felts ashamed, like a freak. Friends flippantly tell me to get a wig, not knowing how uncomfortable a wig can be. I'm trying to rise above it, to embrace my very visible baldness. Some days are better than others. This is an area we can be desperate for a cure, a treatment and we are vulnerable to the snake oil salesmen who promise us they have a cure. None of them work. At the least, their sham cures cost us money. At the worst, the supposed cures can injure our health.

Dona Kendall, Indiana

I was diagnosed with alopecia totalis in 2008 and still in 2017 I'm not bold enough to go without my wig I am a 66 and it's very hard to explain hey this isn't cancer no one talks about alopecia it's like the Forgotten child

Yvette Sethy-Callahan, New York

So currently I where a wig because an steroids I have taken have such adverse side effects it is not worth having hair. I have adjusted fairly well now but when I was first diagnosed I was depressed and my self esteem was low because people would stare or assume I had cancer.

Teresa Thomas, North Carolina

I think all health care should be trained on what Alopecia is and the side affects of having a Autoimmune disease instead of guess why your hair fell out and the cause I’ve had it for 30 years and I’m 54 still being send to dr after dr and still don’t know no more than when my hair fell out it also need to be brought up in the school system and job some ppl don’t think it something contiguous and more research available for ppl to read and know what Alopecia is

Anonymous, Massachusetts

I would like to see more options for alopecia areata/universalis

Anonymous, New York

My problem started when I was diagnosed with a Thyroid condition.
95% of mythyroid was removed, because it was diseased.
Since that time I went to several big hospital and good doctors, advising them I am losing my hair.
All disregarded it. ALL.
I believe my hair loss was due to my Thyroid condition. My numbers were all over the place. And when it wasn't , I did not lose any hair.
Now I have lost 80 % of my hair. I am taking more vitamins. I wonder if that was all I needed the doctors to stay on top of.
But this is what I am living with. And the medical community is moving so so slow, to find a solution.
What does it take, when blood has to be giving twice a year, to also check to see if your body is low on nutrient deficiencies.
Low iron also causes hair loss.
What does it take.
Endocrinologist need to be reinstructed. Hair loss is so prevalent.
Also the cost, incurred by the patient. It is so expensive to buy different items that actually doesn't help.
So please, move slowly, read our comments. And please also keep all the doctors on top of your findings.
Thank you.

Cheressa Mora, New Mexico

My son has alopecia and he has learned to deal with it...he don't have community support and we have no way to get to the events since they are mainly out of our state. From my point of view it would be nice to help support the kids of New Mexico by having an event here so that they too can be aware that there are more out there not just them.

Ali Mohammed, Pennsylvania

I believe if the FDA puts in enough funding then more research will be conducted to eradicate this devastating condition.

Anonymous, Pennsylvania

Alopecia is a condition that needs more attention. So many individuals are affected but silent because of the perceived embarrassment linked to baldness, especially if female. It affects young and old people of all races, religions and ethnicity. Too little effort has been paid to this condition and that needs to change.