

## MEETING MINUTES

NOVEMBER 25, 2014

### GENERAL ITEMS:

- We were very lucky to have a Naturopath, Dr. Jonathan Prousky join us to answer all of our questions. Please see the chart below with his answers to our formal questions.
  - The Kelation test is very expensive and not recommended because it does not have much to do with CA
  - Lactose Intolerance can cause malabsorption and enzymes diminish with time (in Caucasians). You can benefit from digestive enzymes
  - Plaquenil has no contraindications and is ok to use. Regular monitoring is required.
  - Multiple Auto Immune Disorders – In this case, a higher amount of women will have an under active thyroid. Vitiligo, Lupus and Scleroderma can also be present.
  - Getting the Flu shot is okay for us CA suffers

### QUESTIONS FOR DR. PROUSKY, ND:

\*CA = Cicatricial Alopecia, CCCA=Central Centrifugal Cicatricial Alopecia, FFA=Frontal Fibrosing Alopecia

#### Treatment

<ul style="list-style-type: none"> <li>• In your clinical experience, what vitamins/supplements are most effective in treating scarring alopecia? How long do they take to work? How long is the course of the vitamins/supplements? Does the condition relapse upon discontinuing the vitamins/supplements? (Please specify if the vitamins/supplements differ depending on the type of scarring alopecia.)</li> </ul>	<ul style="list-style-type: none"> <li>• Medications have more research to back them up</li> </ul>
<ul style="list-style-type: none"> <li>• Are natural DHT blockers effective in treating scarring alopecia (e.g., Saw Palmetto)? Are there others?</li> </ul>	<ul style="list-style-type: none"> <li>• There may be a chance that this treatment can help androgenic alopecia</li> </ul>
<ul style="list-style-type: none"> <li>• I've heard that low iron and low zinc can cause hair loss; what are appropriate levels of zinc and iron for healthy hair?</li> </ul>	<ul style="list-style-type: none"> <li>• It is a good idea to get your Iron levels measured. If you are a woman and your Iron is below 70 you should be taking supplements. Most women will not have good levels and post-menopausal women will have big Iron stores. Basic shedding can be slowed down but you should always</li> </ul>



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	<p>be supervised by a medical practitioner.</p> <ul style="list-style-type: none"> <li>If your Zinc is low, you can take Lysine (Amino Acid) which will increase the absorption of Zinc.</li> </ul>
<ul style="list-style-type: none"> <li>What might be the cumulative effect of all the binders and fillers in vitamins, supplements etc. If we are taking a number of these daily, over years, any thoughts?</li> </ul>	<ul style="list-style-type: none"> <li>The good quality vitamin companies will limit the fillers</li> <li>Regulations are pretty strict here</li> <li>The professional brands are the best (Thorne, Cyto-matrix)</li> </ul>
<ul style="list-style-type: none"> <li>What herbs or spices do you recommend in treating LPP (e.g., turmeric)?</li> </ul>	<ul style="list-style-type: none"> <li>Any that improve inflammation all over the body are a good bet (GCA, Curcumin, Turmeric, Bromaline)</li> <li>Do not use all at once</li> </ul>
<ul style="list-style-type: none"> <li>Based on potential correlation of LPP/CA with high testosterone levels in male patients – is there a test available that would be able to determine presence of high testosterone levels? And if so, are there natural foods or products to bring it back to normal levels?</li> </ul>	<ul style="list-style-type: none"> <li>Yes, there is a test that the doctor runs all the time, to test hormone levels</li> <li>DHT should be tested</li> <li>You need to ask specifically for this test and it is \$60</li> <li>Reducing DHT levels does not affect testosterone levels in men</li> <li>Use flax seed powder (1 tbs, 2x a day)</li> </ul>
<ul style="list-style-type: none"> <li>Have any non-drug therapies proven to reduce inflammation? If so, what are they?</li> </ul>	<ul style="list-style-type: none"> <li>Diet and supplements</li> </ul>
<ul style="list-style-type: none"> <li>What are your thoughts on vitamins (e.g., biotin, iron, saw palmetto, fish oil) in treating the inflammation causing the scarring alopecia?</li> </ul>	<ul style="list-style-type: none"> <li>Niacin can help with hair loss and will cause your skin to flush because it brings blood to the skin. A negative effect is that it will cause itching and burning but this will be a topical local reaction.</li> <li>All above is to promote growth in the non-scarred areas of the scalp.</li> <li>Saw Palmetto can help with hairloss and it will lower androgens indicated in hairloss.</li> <li>Spearmint tea is good for treating androgenic hairloss. (Take it as a tea.)</li> <li>Vitamin D should be bumped up to above 100 (also associated with general wellbeing)</li> <li>All supplements can be taken together, hydrochlorics should be with food and Lysine should be on an empty stomach with Iron.</li> </ul>



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<ul style="list-style-type: none"> <li>• What do you think the difference is between medical treatment of alopecia and a holistic / natural treatment plan?</li> </ul>	<ul style="list-style-type: none"> <li>• Medical treatment is always evolving</li> </ul>
<ul style="list-style-type: none"> <li>• Can a holistic/ natural treatment plan work without going 100 percent off drug treatments?</li> </ul>	<ul style="list-style-type: none"> <li>• No comments</li> </ul>
<ul style="list-style-type: none"> <li>• Any advice on how to protect the hair that we have left?</li> </ul>	<ul style="list-style-type: none"> <li>• No comments</li> </ul>

### Diet and Health

<ul style="list-style-type: none"> <li>• Are weak &amp; brittle nails and thin hair a sign of protein deficiency? I've noticed that my hair loss increases at times when my nails are weak and brittle.</li> </ul>	<ul style="list-style-type: none"> <li>• This can be a sign of a deficiency in absorbing acid in the stomach (Hydrochloric acid deficiency)</li> <li>• Take supports for the stomach – take 1500mg hydrochloric acid, not with Advil, steroids or ulcers and with supervision</li> </ul>
<ul style="list-style-type: none"> <li>• Is there a link between hair loss and malabsorption or other digestive issues i.e. IBS, Inflammation of the gut etc.? What are the signs of vitamin and mineral malabsorption?</li> </ul>	<ul style="list-style-type: none"> <li>• Yes, additionally they will rule of celiac disease</li> </ul>
<ul style="list-style-type: none"> <li>• How accurate are heavy metal/mineral hair analysis tests? Can heavy metals cause hair loss?</li> </ul>	<ul style="list-style-type: none"> <li>• Tests are accurate</li> <li>• You would have other major issues aside from CA if you were toxic</li> </ul>
<ul style="list-style-type: none"> <li>• I've heard that hormone imbalances can cause hair loss. Which hormones would cause these imbalances?</li> </ul>	<ul style="list-style-type: none"> <li>• DHT and lower SHBG</li> </ul>
<ul style="list-style-type: none"> <li>• We hear so much about anti-inflammatory foods such as salmon etc. Do they play a significant role in CA? Obviously, they are good for health overall</li> </ul>	<ul style="list-style-type: none"> <li>• Omega 3s</li> <li>• PPARs are depleted in patients with IBS and certain CAs – if you increase them, you lower inflammation</li> </ul>
<ul style="list-style-type: none"> <li>• Which foods are anti-inflammatory and which are inflammatory?</li> </ul>	<ul style="list-style-type: none"> <li>• Seeing a registered dietitian is the best option</li> <li>• The Mediterranean diet is a good diet to follow for treating inflammation</li> </ul>
<ul style="list-style-type: none"> <li>• What should you look for in fish oil and what dose is recommended?</li> </ul>	<ul style="list-style-type: none"> <li>• Good quality and professional brand</li> </ul>
<ul style="list-style-type: none"> <li>• Do you think that diet plays a role in increasing or reducing inflammation? If so, what diet would you recommend?</li> </ul>	<ul style="list-style-type: none"> <li>• The Mediterranean and the Japanese's diets are good</li> <li>• The Japanese diet has a low cancer rate</li> </ul>

### Research

<ul style="list-style-type: none"> <li>• Which books or magazines seem most reputable in your opinion? There is such a proliferation of new information, ads etc. What can one believe? Even peer reviewed medical journals (like JAMA) have made</li> </ul>	<ul style="list-style-type: none"> <li>• You should be critical and logical when reading and following information</li> <li>• Scientific papers are a good and reliable source</li> <li>• The quality of the article is important</li> </ul>
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mistakes so how do we know what information is legitimate?	
<ul style="list-style-type: none"> <li>Is there any known link between hormone imbalances and the immune response that causes scarring alopecia?</li> </ul>	<ul style="list-style-type: none"> <li>It is primarily an immune system issue</li> <li>It is good to look at hormones because they can impact but are not primary cause</li> </ul>
<ul style="list-style-type: none"> <li>Is there any known link between nutritional deficiencies/protein malabsorption and the immune response that causes scarring alopecia?</li> </ul>	<ul style="list-style-type: none"> <li>No comments</li> </ul>
<ul style="list-style-type: none"> <li>Can you address any new research, treatments, or observations for the different types of scarring Alopecias (LPP, FFA, and CCCA)?</li> </ul>	<ul style="list-style-type: none"> <li>No comments</li> </ul>
<ul style="list-style-type: none"> <li>Is there an increase in Cicatricial Alopecia cases in Canada in recent years? If so, why do you think that is the case?</li> </ul>	<ul style="list-style-type: none"> <li>No comments</li> </ul>
<ul style="list-style-type: none"> <li>Do you have names of naturopaths who are familiar with our condition?</li> </ul>	<ul style="list-style-type: none"> <li>Any naturopath who is dedicated will work with you but be aware of doctors that are mostly out to make money</li> </ul>

#### STANDARD MEETING ITEMS:

- All \$20 annual dues collected from members have been used for meeting snacks and to host the website. If anyone has any suggestions on ways to spend the money, please submit to Shirley. As noted, the website needs to be upgraded to accommodate additional functions like question submission. (See action items) If you have not paid your 2014 \$20 dues, please bring it to our next meeting and see Erynn.
- We should resurrect the original list of survey questions that we had started gathering as a group a year back. These questions are representative of what we are all wondering and looking for answers for. Examples include, "Does any CA suffer have any other immune diseases?", "Has anyone suffered any head trauma in their past?", "Does anyone else have vitiligo?"
- Our member Hatcho runs a Facebook site for scarring alopecia. To join, send him a message through the site here... LPP Lets Put Out the Fire <https://www.facebook.com/#!/groups/179660093699/>
- Please let Shirley know if you would like to give your contact info to any of the other members and she will facilitate the connection.
- Next meeting is at 6pm on Tuesday March 31st at 2200 Yonge Street.** (See directions attached [Directions to the Canadian Tire Conference Centre.docx](#))
- March agenda:
  - 5:30 - 6:00 Room opened and member check-in (New member orientation if required)
  - 6:00 - 6:20 Welcome new members to the group
  - 6:20 - 7:45 Meditation introduction and session for dealing with stress with Angela
  - 7:45-8:00 General CASA updates on fees, website, upcoming Canadian Skin Patients Alliance meetings
  - 8:00 Meeting is adjourned (Mix and Mingle)



## PREVIOUS MEETING ITEMS:

- Chair and Co-Chair positions within CASA are still open. Any interested people should contact Shirley.
- Is there a need to incorporate CASA or become a registered charity?

## NEXT STEPS

### **Next Meetings:**

Tuesday March 31st, 2015 from 6:00 pm – 8:00 pm

Tuesday June 23<sup>rd</sup>, 2015 from 6:00 pm – 8:00 pm

Tuesday October 6<sup>th</sup>, 2015 from 6:00 pm – 8:00 pm

2200 Yonge Street, Canadian Tire Conference Centre