CASA Jan 20/June 16 Meeting – Questions for Dr. Donovan

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

GENERAL	**DR. RESPONSES**
1. Is scarring alopecia an autoimmune disease?	CCCA is not autoimmune. Typically, the body is weak and the immune system is too good; it is an immune problem.
2. Does having scarring alopecia put us at a higher risk for developing other autoimmune diseases?	Probably yes, there is a possible type 2 diabetes development in CCCA patients. Hypo thyroidism can occur, but is rare.
3. Why does scarring alopecia mostly target the hair follicles on our scalps and why only certain scalp-hair follicles?	LPP and CCCA are only present on the scalp. Other CA types can target other body parts. In generic hair loss the hairs get thinner.
4. Is scarring alopecia genetic?	Textbooks say that is it not genetic but there may be a slight increase that it is genetic in LPP family members. CCCA does have a genetic risk.

CAUSES/TRIGGERS	
5. What's your theory of the cause of this condition?	In all types of CA, 12 of the types are quite common and 20 are rarely ever seen but each type has a different thought behind it. In LPP, the immune system is hypo activated and there is something that is causing this. Could be anything. In FFA, we do not know. In CCCA, relaxing and straightening of hair has been studied.
6. Is there any known link between hormone imbalances and the immune response that causes scarring alopecia?	In FFA, the only CA in this case, there has been a study that focuses on the associations between hormones. Female hormones decrease and male hormones are increased.
7. Is there any known link between nutritional deficiencies/protein malabsorption and the immune response that causes scarring alopecia?	There is no evidence (or studies) between gluten free diets and CA.
8. Does sweating from the scalp aggravate scarring alopecia (e.g., exercising)?	Sweating does not aggravate the disease but increasing the body temperature in exercise, stress and summer weather can lead to itching. (A max of 20 Degrees Celsius is recommended to help reduce symptoms.)
9. Is LPP is more aggressive in cases triggered by scalp trauma than in	Some people can get LPP because of scalp trauma. Transplants, burns and impact can

cases that trigger spontaneously? Is there a difference in the course, treatment or burn-out time between each mechanism?	be factors. If you have LPP from trauma, you would be less likely to have other aspects of the disease.
10. Is there any known link between poor dental hygiene and scarring alopecia?	No evidence, a study with multiple people would be needed. In order to do a really good study, you need thousands of patients.

TREATMENT

Drugs

11. In your clinical experience, what drug is most effective in treating scarring alopecia? How long does it take to work? How long is the course of the drug? Does the condition relapse upon discontinuing the drug? (Please specify if the drug differs depending on the type of scarring alopecia.)	Most common CA (FFA, LPP and CCCA) is treated with the same Cortical Steroid injections with Plaquenil and/or Doxycycline. 40 –50% do well with these meds and the rest go on to use other meds. The drugs can take up to 6 months to work but is different for everyone. Once the condition stays quiet, 80-90% of the time the meds can stop. Injections are the first treatment to stop when symptoms are gone then the other treatments will follow. Photos can be used to track the progression of the CA.
12. Are these drugs aimed to *slow down* the hair loss or can they *stop* the hair loss?	The goal is to stop the hair loss. In some cases, the hair loss is stopped all together and in others it slows down. In the earliest stages of CA, stopping the loss is possible. Microbyomes are collections or pockets on the scalp where we have different bacteria. In some individuals they can trigger the immune system and effect the CA. Only in rare CA types. Antibiotics help to clear some of the microbyomes but it is not known whether the play a role in LPP.
13. In your clinical experience, what is the success rate of plaquenil?	There is a 50% success rate in FFA, 60-70% in LPP. In both cases, 30% of patients say that it stops. In general, if someone has not had good results with a drug, they will not be put back on that drug.
14. One side effect of plaquenil is alopecia so how can it be prescribed to treat it?	Plaquenil caused hair loss, if any, is temporary and rare at 1/400. There may be shedding for the first 3 months after starting Plaquenil.

15. What is its effectiveness of doxycycline? How long does it take to work? How long is the course of the drug? Is there benefit to taking a shorter course for those who don't want to be on it for a long time?	Doxycycline is an antibiotic in the Tetracycline family and it helps in 50% of LPP, FFA (25%) and CCCA (60%). It will usually start working within 3-4 months and is typically taken 2 times a day. 6-8 months is needed to really see if the drug is working. It should be taken consistently and can be tapered down once the disease is showing signs that it has stopped.
16. What are your thoughts on using Rogaine to treat scarring alopecias? What is your recommendation on usage? How many doses can be skipped without losing any hair?	Rogaine should be used 4-5 times a week and can be used for all types of Alopecia. Rogaine tells the follicle to grow and can also cause itching and shedding so it is not recommended right away. Rogaine and Dutasteride can work together, Rogaine works on the follicle and Dutasteride works on hormones. Rogaine is cheaper and over the counter in the U.S.
17. Are DHT blockers effective in treating scarring alopecia? Should patients being treated with DHT blockers (e.g., Avodart) undergo periodic screening for cancer?	Hormone blockers are used in men to treat balding. In FFA, hormone blockers can work, but there is no other evidence that they work in the other CA's. In men, they can reduce prostate cancer risks. Periodic screening for cancer should be completed.
18. How is the treatment of scarring alopecia different from other types of non-scarring alopecias that seem to have the same appearance (e.g., men with "shiny" bald heads)?	Treatments are very different. Many conditions can look the same. What happens to the scalp in each case is different and in CA the scar is your body trying to stop the inflammation in the follicle. 30% of people have no inflammation in LPP and many more have no inflammation in FFA.

Injections and topical corticosteriods

19. Do you still recommend regular Kenalog injections?	Steroid injections are one of the best ways to treat all types of CA. There have been good studies that show that they are very safe.
20. Has there been any significant regrowth in patients who are receiving injections and/or topical corticosteriods?	Yes, in some cases of LPP, about 25%, (FFA it is rare) people need only the topical and the injections to make an improvement.
21. Will the dents in a scalp caused by the Kenalog injections go away?	Yes they will, provided that you do not inject in that same area again.

22. How long does it take for injections/ corticosteriods to work? When should patients forgo them if they don't seem to be working?	The injections work quickly, within one week patients will know whether they feel better or not. Some patients will get their symptoms back and will need to try more injections. Injections should not occur more frequently than every 3 weeks.
23. What's the longest time period someone should be receiving injections for?	If after 2 sessions they do not work, the patient can stop getting injections. It is important to check bone mineral density after 3-4 years plus regular visits to an Opthamologist is important if eyebrow injections are occurring. There is a small group of patients that actually get worse with injections. It is potentially the scalp trauma of receiving the shots. (20mg every 8 weeks is the safest dose.)
24. Some patients are using multiple topical scalp treatments. In what order would you apply these products to ensure effectiveness?	All of the topical treatments get absorbed into the body. These are safe under the direction of a dermatologist. Clobetasol is the strongest, then Dovobet, Lyderm, Lidox, then Betamethasone, Betaderm, then Hydroval and then derma-smooth which is very safe. Use either steroid then Rogaine or Rogaine and Protopic. Use the steroid first then non steroids and Rogaine can be used on top. (Rogaine is not used very early in the treatment) Use Rogaine under greasy treatments. Try to alternate uses. Rogaine can cause scaling in some people. These treatments can cause thinning of the skin in FFA and blood vessels may become visible. Clobetasol bottle should last 6-8 weeks.
25. Some FFA patients are finding the remaining hair at the front of their scalps has changed significantly in appearance (curly, fuzzy, and wispy)? Is this caused by the disease or the treatment (e.g., by the topical applied to the front)?	Hairs will change as they push through the scarring on the scalp. This can cause a different texture in the new hairs. In CA, scars cover the follicle and the hairs either try to fight through or the hair stops because of the inflammation and does not even bother to grow. In the first months of the CA, the follicle is not dead. Some gels and lotions can have alcohol in them which can cause dry scalp and can change the texture of the hair as well.

26. What is most effective in treating eyebrow loss in FFA patients? Can they regrow?	A session of injections into the eyebrows early on in the disease is recommended and can help. Once the eyebrow hair is lost, it is very hard to regrow. A study in 2008 of 12 patients found that 1 of the patients said that they injections did nothing; two said that they had a lot of regrowth and three to four said that there was an improvement. Lumigan (which became Latisse) is traditionally used to treat glaucoma but can be used for eye lashes.

Non-drug therapies

27. Have any non-drug therapies proven to reduce inflammation? If so, what are they?	Not a lot of good evidence that non drug therapies help. Castor oil and Curcumin have been shown in some cases to reduce inflammation in the body. (Turmeric is similar.) Vitamin D is recommended for all CA patients (2000 units a day is safe). Most people are deficient inVitamin D. There is not a lot of evidence that non-drug therapies work for CA. Biotin and Ginger have not been shown to help and there is no scientific evidence that Emu Oil helps.
28. Do you think diet plays a role in increasing/reducing inflammation? If so, what diet would you recommend (e.g., gluten-free, dairy-free, "night-shade vegetable" free)?	This is no evidence for this but a clean diet is helpful for overall well-being.
29. What are your thoughts on vitamins (e.g., biotin, iron, saw palmetto, fish oil) in treating the inflammation causing the scarring alopecia?	There is no evidence that Biotin helps CA. Low iron is common in premenopausal women. Iron and thyroid function should be examined. Saw Palmetto can block hormones in some cases but does not need to be taken at the same time as Dutasteride. Fish oil (3/6/9) may be helpful to reduce inflammation.
30. If the immune system is causing an immune response to trigger	In CA, the immune system is too active so CA patients should not take Cold FX or

inflammation in the scalp, then why aren't treatments offered to boost the immune system or an immunologist involved in the treatment? Are there such treatments out there?	Echinacea as we want to quiet it down. Clinical immunologists are typically involved in studying different allergy types. Autoimmune diseases are studied by their specific specialist (e.g., Dermatologist for Alopecia and Rheumatologist for Fibromyalgia)
31. Are hair transplants /hair cloning an option right now for scarring alopecia patients? If not, do you think they will be in the future?	Cloning is not an option at this time; it is being researched and tested at this time by only 5 companies in the world. Transplants will only be considered if the CA has been quiet for a year or two with no symptoms. Once the CA becomes quiet (no meds), it usually stays quiet but trauma can reactivate it. Dr. Angela Christiano at Columbia University is the source of the cloning information. She had Alopecia Areata at one time.

**This is where the Q & A discussion stopped and continued on June 16th 2014.

SYMPTOMS/BEHAVIOUR

32. Have you seen the facial papules caused by FFA disappear with treatment? If so, what treatment has proven to be more effective?	Not seen in everyone with FFA, about 15-20%. There has not been enough studies to show whether they disappear. Good treatments include, Finasteride and Dutasteride. It seems that the oil glands are affected as opposed to the hair follicles.
33. Can scarring alopecia cause eyelash loss, too?	Yes, FFA patients can see a reduction in eyelash density that is not typical in LPP, CCCA and others. Latisse/Lumigan seems to help in most cases.
34. Do most patients with FFA experience hair-loss on other parts of their bodies? Why are only certain areas targeted?	Yes, no one knows why this happens. FFA was only first described in 1994.
35. Does LPP scarring take place exclusively under the skin (invisible on the surface)? If not, what does visible scarring look like in LPP patients?	In LPP, the scarring is exclusively 2 mm below the skin. There are 40 different scarring Alopecias and the scalp is usually smooth with no follicles visible.
36. Is there any evidence that cutting hair short reduces tension on follicles and reduces symptoms or aids recovery?	No, tension does not play a part. Cutting the hair short for people with folliculitis is important and helps the treatments get close to the scalp.

37. How common is it that LPP (not FFA) would target the hairline?	LPP is typically seen in a circular pattern. Some patients have both LPP and FFA. Only 5% of LPP patients will have a reduced hairline.
38. Is itchy skin (eczema, contact dermatitis, rashes) more common?	No, but Eczema can occur in 20% of the entire population.
39. Is there a typical/average burn out time for FFA, LPP, and CCCA? If so, what is it?	A proportion of patients do burn out without treatment. 75% of patients overall will burnout. There is good evidence that the medications work. Using a photo journal is a good way to see the progression or the halt of the progression. In LPP, burn out will mean that symptoms are gone. 10% of LPP patients do not have symptoms. In FFA, burnout will mean that the progression has stopped. In CCCA, measurements can be used to track progression. Stress will usually cause flair ups.
40. Will the hair loss stop before we lose most of our hair?	This depends on the cause of the hair loss and the progression to date.

RESEARCH

41. Can you address any new research, treatments, or observations for the different types of scarring Alopecias (LPP, FFA, and CCCA)?	The following are the latest observations: LPP – Oil glands are the first target of the disease, chances of thyroid issues may be slightly higher FFA – hormone blocking medication seems to have promising results CCCA – less research, if treated early and aggressively, hair growth can reoccur
42. Is there an increase in Cicatricial Alopecia cases in Canada in recent years? If so, why do you think that is the case?	FFA rates have gone up across all countries in the northern hemisphere, mostly in Caucasians. No recent LPP increase. CCCA has increased in the last 20-25 years and could be related to hair styling in black women. There was a study in the UK that looked at the socio-economic status of FFA patients. The study found that patients were typically mid to upper income and theories include exposure during travel (post 1994) but hair products were not validated.
43. Can you talk about the new hair follicle neo-genesis research by Angela M. Christiano (co-author)? Reports say this could be a break-through for	Neo-genesis has cause hair growth in mice (new follicles). Hairs will grow well in scar tissue if the condition is not active.

people with burns and scarring alopecia. If this research turns out to be as good as it looks, will there still be the issue of transplanting into scar tissue or does this technique somehow get around that problem?	
44. Is there any medical proof that scarring alopecia may later turn into a more serious disease?	This is not a concern with LPP, FFA and CCCA. In Discoid Lupus, 5% of female patients develop Lupus in the body. Sometimes, skin cancer chances are higher in Discoid Lupus. There is really no reason for CA patients to be screened for Lupus specifically unless symptoms are present.

OTHER

45. Do you have a list of dermatologists who are familiar with our condition?	All dermatologists are trained in Skin, Hair and Nails. Only two in Canada are exclusive, Dr. Gerry Shapiro and Dr. Jeff Donovan. In addition, there is Chantal Bolduc in Quebec, Renee Beach and Charlene Linzon in Toronto. Call the Canadian Dermatology Association for more information about a dermatologist near you.