Eye Disease and Treatment- March 19, 2024 Patient Education Webinar

Becky Strong: Welcome, everyone. This webinar is now being recorded. I'm Becky Strong, IPPF Outreach Director, and I'll be your host for today's webinar. I would like to thank you for being on the call with us today. Before we begin, I want to remind everyone that “Information is a key factor in treating and living with any condition. However, everybody's situation is unique. The IPPF reminds you that the information found online or during a presentation like this should be discussed with your doctor or healthcare team to determine if it applies to your specific situation”. Today, we're excited to have Dr. Djalilian with us to discuss eye disease and treatment. But before I hand it over, I just want to introduce you to him. Dr. Ali Djalilian is the Searls-Schenk Professor of Ophthalmology at University of Illinois at Chicago. After completing medical school and residency at University of Minnesota, he completed a uveitis/ocular immunology fellowship with Robert Nussenblatt at NEI followed by a cornea/ocular surface fellowship with Edward Holland at Cincinnati. He then completed research postdoctoral training in epithelial biology at NIH before starting his academic career on the cornea service at University of Illinois at Chicago. Clinically, he is a leading expert in the management of severe ocular surface disease, including cicatricial conjunctivitis. He is currently the co-Director of the Cornea Service at the Illinois Eye and Ear Infirmary. His research interests are in regenerative medicine where he aims to develop novel therapies to restore the function of the cornea. Welcome Dr. Djalilian. So before Yeah, before we begin, I just want to go over some housekeeping items...(Reviews Housekeeping Slides).
And it is now my pleasure to hand it over to Dr. Djalilian.

Dr. Djalilian: Thank you, Becky. It's my pleasure to be here. And with our audience here. I hope I can provide you some information about the eye involvement in these conditions. And happy to answer questions that have been raised. So my presentation is going to be relatively brief because I want to leave more time for the questions. I think that's where I can really get into it. Give me a minute here.

Becky Strong: That's okay, we appreciate the time that you put into this presentation and for being with us today. It's a real honor to have you here. So thank you.

Dr. Djalilian: Thank you. Thank you so much. I'm sure many of your audience know pemphigus and pemphigoid are two distinct conditions. There are multiple subtypes. I will start by focusing on pemphigoid and the eye involvement and at the end briefly touch on pemphigus since eye involvement in pemphigus is definitely less common than pemphigoid. So I think there was a question on this as well on the terminology. Mucous membrane pemphigoid sorry I didn't spell it out here but MMP, mucous membrane pemphigoid, this is the general term. OCP or ocular cicatricial pemphigoid was an older term. Now, we don't use that as often just to indicate that this is not strictly an ocular disease, it could be other mucosal membranes that could be involved. Ocular MMP is sometimes used. Sometimes we'll call it drug induced MMP, and we'll get into that with conditions where we think topical eye drops could be triggering an MMP like condition. And a more very general term in terms of if we want to describe the severe form of the ocular disease, is what we call cicatricial conjunctivitis. Anytime we see scarring in the
conjunctiva, conjunctival inflammation that is leading to scarring, we'll use the general term cicatricial conjunctivitis and this is not exclusive to pemphigoid there are many other conditions that can also cause this.

**Dr. Djalilian:** So pemphigoid when I mentioned pemphigoid I mean, this mucous membrane pemphigoid this is a typical presentation of the eye disease. Not everyone is going to develop eye disease. I think the estimates are anywhere from half or more may develop the eye disease and the severity is going to vary. But the eye can sometimes be the initial presenting organ and the symptoms would be chronic red eyes. Chronically inflamed eyes, that over time lead to some scarring changes. Here, you can see if we flip the lower lid down, and we can see some of these linear changes, these white lines on the back side of the eyelid, basically, leading to scar formation here. That's the result of chronic inflammation. So any chronic inflammation on the surface will do this. It could be from other ideologies as well. So any time the eyes are chronically inflamed, and we don't control the inflammation this can lead to scarring. And then if there's scarring here, then this will start to alter the position of the eyelid and this can start to cause the eyelashes to be turning inward a little bit because the scarring is pulling that eyelid a little bit more inward.

**Dr. Djalilian:** But in a case of pemphigoid, or mucous membrane pemphigoid, as many people know, the underlying issue is an autoimmune condition. Meaning the immune system is mistakenly sort of becoming active in the mucosal surfaces. And by mucosal surfaces, I mean all these wet surfaces, wet like the surface of the eye, inside our mouth, inside our airways, or inside the genital/urinary tract. This autoimmune response could happen in these mucosal surfaces as a result. It seems like what it's targeting primarily is this, what we call the basement membrane. The very surface of all these tissues that we're talking about, the surface of the eye or surface of the mouth, they have a layer of cells that we call epithelial cells, and beneath the epithelial cells is a layer, it's a very, very thin layer that's called the basement membrane. That's what the epithelium sits on. Here you can see, if you tissue and make a section of it and look at it under a microscope then you can see here this is all those epithelial cells which are on the surface, and this layer here is the basement membrane. So it seems like this is the primary target tissue, that is that the immune system is mistakenly thinking that there's something going on here and it's forming mostly an antibody response. The immune system is forming antibodies against some things that it's seen in the basement membrane or what we call autoantigens. This is the confirmatory test for making the diagnosis. Taking a biopsy, small tissue biopsy from the mucosal surface that is involved, and to see whether there's evidence of antibodies or immune activation along the basement membrane. In addition to that, you can also look for certain antibodies circulating in the blood as well, and that also provides some additional confirmatory information. So this autoimmune attack is happening even if the eye is just involved, it's a sign that the immune system is misbehaving but it's choosing to go to the eye or to the mouth. Why it chooses one tissue, but not the other, none of that is known. But certainly any things that that can trigger, let's say sometimes it could be trauma or something like that, and tissue that that may contribute to it.
**Dr. Djalilian:** Like I mentioned before, really for many patients if their eyes are going to be involved the eyes will become inflamed. In other words, the eyes will be chronically red and that's a sign of inflammation. That redness is just the immune system being active on the surface of the eye and when there's inflammation, inevitably, the eyes also start to feel dry as well because after a while that inflammation affects many of the tear regulation and production on the surface of the eye. Chronic inflammation and dryness sort of go hand in hand.

**Dr. Djalilian:** Again, with pemphigoid, like we said early on, it's just little scarring changes, but then there could be more scarring. With time again, if the condition is not diagnosed or controlled, then over time, typically this is not on the order of weeks or even a few months, it's usually like years, it progresses to have more extensive scarring. This image shows a very end stage, this would be a patient that went undiagnosed for a very long time and did not have access to care. So then there could be scarring to the surface of the eye, that can become very visually important.

**Dr. Djalilian:** So the most important aspect of the treatment really is to control inflammation and to control immune responses. As far as the eyes, the only marker of disease activity that we really have is how red the eyes look and how inflamed the conjunctiva looks because the scarring progresses very slowly. So from one visit to another, let's say within a few months, it is not likely that we're going to see enough changes in the scarring. I mean over a year or two, maybe we'll see scarring if it's progressing but not not over a short period. So the only way for us to know that we have the condition under control is to look at the inflammation in the eye. The goal is to try to get the eyes so they're not red. We can get a patient who has chronic red eyes and get him to the point where the eyes are not red and we know that the disease is under control. It's not progressing or not likely to be progressing.

**Dr. Djalilian:** So that has to be done. Again, this is highly variable from patients in terms of how much treatment is needed. There are patients that we can manage with just minimal medications, some require more so it's highly variable from patient to another. Typically they will be on some combination of medications and many patients may already if they've had a diagnosis, they may already be on some of these treatments for their disease for other organs or tissues that have been involved. These are all medications that generally are used to control immune responses, to calm down the immune system. One of my favorites is Mycophenolate, it's a fairly safe medication that works well to control inflammation. Steroids, we don't really use them long term, short term we'll use oral steroids. Dapsone has been used for many, many years. And I occasionally use it if Mycophenolate is not sufficient, then maybe I add some dapsone. But again, many people use it as first line as well and that's fine. It does require a little more monitoring of the blood count, the hemoglobin. For more severe conditions or very severe disease that really has not been controlled, then these last group of medications can be used. It's rare that we have to use those. Now with the use of biological medications that target very specific aspects of the immune system. Now it's rare that we go to those, we call these alkylating agents. There are medications that target the B cell component of the immune system, Rituximab being the classic one. IVlg are immunoglobulins that have been collected from healthy donors, and they've been pooled together and that seems to have an anti
inflammatory effect. It's given as an infusion as an IV, same with Rituximab. Then there are these TNF, tumor necrosis factor, inhibitors that are also used occasionally. Most patients don't don't have to be on those for the TNF inhibitors.

Dr. Djalilian: Some other medications that I typically will use as an adjunct to help, there's a class of antibiotics, tetracycline, doxycycline, and minocycline, being the common ones that are used. They have some antibacterial effects, but also have anti inflammatory effects. Again, that seems to have some additional beneficial effect for the surface. There's some patients with very mild disease that I just use this alone and that's sufficient to control their level of inflammation. Omega-3 fatty acids, there might be benefits to them for some additional anti inflammatory effects. I don't always make the patient take it, but I'll mention it to them as something else. Omega-3 in general, I think that the story seems to be that the more we can get this from the food the better it works, then as a supplement. If we're eating more fish that is high in omega-3 that seems to have a better effect than taking it as a supplement. But there's evidence that the supplement also helps. Patients can also use some eyedrops to help control inflammation. One of my favorites is tacrolimus. But also I neglected to mention cyclosporine. Tacrolimus and cyclosporine are both medications that target T cells of the immune system. Cyclosporine which comes in various commercial names. Basically, these two work the same mechanism, they're basically targeting T cells. The nice thing about them is that they're very safe for long term use, they don't cause any side effects on the surface of the eye and they provide some additional anti-inflammatory effects. This last group are all used for dry eyes in general. So they should reduce inflammation in dry eyes but we use them as an adjunct in patients with active surface inflammation. For tacrolimus the only approved form here in the US is the ointment form, the drops have to be compounded. Occasionally for some patients we have to keep them on a little bit of low dose steroids from time to time, or even once a day or once every other day, just to keep things quiet. And we tend to use milder steroids to minimize the side effects.

Dr. Djalilian: Another important aspect of disease control is controlling lashes because once there is scarring and the lashes are turning, those lashes can contribute to inflammation on the surface by traumatizing the surface. Some patients are comfortable pulling their own lashes as they start to grow inwards, some will have a family member do it. Some will just go into and see an eye physician or an optometrist who will pull them for them on a regular basis. But something else that we also frequently use in these settings is to use a soft contact lens and this provides a protection for the cornea so the lashes cannot touch the cornea. This helps many patients who have frequent issues with lashes. It helps to keep them more controlled, and also helps protect the cornea from trauma, because those lashes can from time to time cause abrasions, and they're uncomfortable for a few days. So many patients are on a regular regimen of contact lens wear during the day. But some patients who are uncomfortable and never get comfortable taking them in and out, we will sometimes leave them in for extended wear. So they'll keep them in for a month or two or something like that, and then go in regularly and have them exchanged at their eye care providers office.

Dr. Djalilian: But for the lashes, there are some more definitive things that can be done. There's cautery that can be done to the lashes to sort of burn off those lashes that are in turning, and then there's actually surgery that can reposition the eyelid. Again, these are best done when we
have the disease under control. I mean, for the cautery, even somewhat controlled is fine, as long as the patient's receiving some kind of systemic treatment. The more definitive surgery to reposition the eyelid, really the disease must be well controlled for at least a year or two.

Dr. Djalilian: And in general, if they're on treatment and they're under control, then they're okay to proceed with other surgeries. But in general, we try not to, say cataract surgery or other procedures, try to minimize anything that specifically traumatizes the surface of the eye.

Dr. Djalilian: So with pemphigus, as we were talking about the surface epithelium, whether it's the surface of the eye or the lining of the mouth. In pemphigoid, it's the basement membrane that's attacked, in pemphigus it's actually a little bit higher up, it's within the epithelium. But pemphigus seems to have much less eye involvement. I really haven't seen that many patients with pemphigus. I mean, I've seen a few, but not that many and the disease doesn't seem to be as severe, in general. I think the subtype that seems more common than others is pemphigus vulgaris. It can happen with any subtype, but in general they could get the same sort of blisters on the surface of the eye, but much less common to see the eye involvement. In general, I guess, any patient with an autoimmune condition that has active inflammation in the body, they can have dry eyes. So first, dry eyes are one of the most common ocular conditions in the world. In people above the age 40, probably up to half of people will have some level of dryness or symptoms depending on their conditions and when they get really stressed their eyes especially spending a lot of time on screen watching screens where we don't blink as much when we're on a computer screen or a cell phone for prolonged periods. So dryness is extremely common but then if you have an active inflammatory disease in the body that can make the dryness worse, just because inflammation can make a lot of conditions feel worse let's say, when there's active inflammation because mechanisms to control inflammation are not working as properly. Anyways, I should say that many of these patients, whether it's pemphigus or pemphigoid, will also have symptoms of dryness. Anyone with dryness, we recommend that they use lubricants on a regular basis. Now as I'm talking, I'm starting to think of things that maybe I could have included here. When it comes to using lubricants on the surface of the eye there many options there but we generally recommend whenever possible to use artificial tears and these are available without prescription, these ones are over the counter. But to use ones that come with no preservative, and they come in single use, small vials instead of a bottle. There are some bottles that are preservative-free that will specifically say, but most commonly the preservative-free ones which are going to come in these small vials. You twist the cap off and you can use the drops but you can still put the cap back on and reuse it the same day but generally you use them for a day or so, not not beyond that, because they're no preservatives to prevent any contamination. In general, most bottles are going to have some type of preservative. Again, it varies some preservatives are more gentle on the surface of the eye, but some of them if the drop is being used multiple times a day, that preservative itself can have an irritating effect on the surface. Which is why there are some patients that we see that develop a scarring, cicatral conjunctivitis on the surface of the eye and these are patients who are on chronic eye drops for conditions such as glaucoma. So a patient that has glaucoma where the pressure in the eyes are high, unrelated to pemphigus and pemphigoid, they're using eyedrops for glaucoma on a daily basis for years, the preservatives in those drops can start to have toxic
and irritating effects over time that trigger this same inflammatory scarring response on the surface of the eye. In general, for any eye drops in these settings, if you're using eye drops on a chronic long term basis, multiple times a day, that is better to use drops that have no preservative. So I think that's about all I had. As I went through that, I thought of some things that I could have put in there, but hopefully they'll come up during the question and answers.

Becky: Great. Well, that was very informational. We did have a couple of follow up questions. There was a question about the fish oil. Is there anything specific we should be looking for? Is there a particular dosage that works well for patients?

Dr. Djalilian: I would say, in general the ones that are derived from fish oil are the best ones. There are variations in terms of the quality of the fish oil. I'm not the expert to say which brands are the best ones? I think there's at least one study that looked at this for eye diseases, and they used I think 600 milligrams. That was sort of the dose that they typically recommend, but I think sometimes they will go up to 1200. I don't use it that often. Give me time and I will give you a more specific answer. In general, personally I'm not as impressed by the additive effect of it, but I think some patients definitely do find it useful.

Becky Strong: Great. Thank you. Then you did mention medications that you frequently use. Is there a protocol or a cocktail of medications that are more successful in putting patients into remission?

Dr. Djalilian: Probably the best combination of medications are those biologicals, Rituximab and IVlg. Again, for milder disease, it doesn't make sense to give those. Those are potent drugs but for someone who has active disease and our typical medications, oral medications are not sufficient to control the disease, definitely Rituximab or IVlg. Rituximab basically gets rid of the B cells for a prolonged period, most of the B cells are wiped out for a period of several months, and then IVlg helps to sort of maintain that inflammation and keep it under control, while the B cells sort of slowly come back.

Becky Strong: Great. Well, thank you so much for that. We have a lot of questions that were submitted before the webinar. So if we could just kind of rapid fire these, and you give us the best answer. So if I was just diagnosed with pemphigoid, when do I start to include the care of an ophthalmologist?

Dr. Djalilian: Great question. I would say, it's not urgent unless they're having active eye problems. But I would say sometime within the first 6 months or so, it would be good to see them. And probably they're gonna say, everything looks fine. We'll see you back in a year unless something changes.

Becky Strong - Great. And can an optometrist treat these diseases? Or do I need to see specifically an ophthalmologist?
**Dr. Djalilian:** Yeah, this is beyond what an optometrist can manage because it requires systemic medications. But I definitely do have a lot of patients that see optometrists to pull lashes for them. So I think they can do that quite effectively. They could help them with the contact lenses. I send patients to them to help fit them with soft lenses, but to actually treat the disease, no.

**Becky Strong:** What's the best way to find an ophthalmologist who is familiar with pemphigus or pemphigoid of the eye?

**Dr. Djalilian:** Good question. So I would say, this falls in the area, mostly of cornea specialists who specialize in the front of the eye. Quite likely because this is not so common, I would say your best bet would be to look for the local referral center or if there's an academic center that you're near, like a university. That's probably going to be the best bet to find people who know about this disease and have managed it. Sometimes a uveitis specialist is helpful, uveitis is the term used for inflammation in the whole eye. So uveitis specialists could also be the ones who take care of these patients too.

**Becky Strong:** Great. That's helpful information. How quickly does pemphigoid spread to the eye? I know you said about 50% of the people that can develop eye involvement?

**Dr. Djalilian:** I don't know if there's good data out there to say what percentage really, because a lot of them could be biased from the fact that they're not seeing the ones who are not developing eye involvement with the diseases. But let's say, somewhere around half, maybe, more or less I don't exactly know. But how quickly does it develop? This is a slow disease so things don't happen overnight. I would say for anyone who gets diagnosed I'd say sometime within that first year they should be seen, and then just follow it over time. I mean, I'm trying to think of patients who came to me after a diagnosis and sometimes it can be years. I don't have a good answer for that one, sorry.

**Becky Strong:** We're all a little bit different and respond to treatments, and I imagine there's a whole slew of things that play into that question. Then you discussed pemphigus causing problems in the eyes. I think we have more questions on our next slide.

**Becky Strong:** What are signs and symptoms indicating that pemphigus or pemphigoid is active in or around the eyes? Secondly, can a blocked tear duct be one of those signs?

**Dr. Djalilian:** I like, I said the symptoms are going to be chronic red eyes. That's gonna be the most basic symptom because it's an inflammation on the surface of the eye. There can also be irritation that goes along with that. A blocked tear duct could be because of the same scarring mechanism that we're showing, that scar could close the tear duct as well. So it could be but if that is the only sign, I would say no. But if it goes along with chronic redness, and maybe even some evidence of scarring elsewhere on the eye, then I would say, yeah, it's likely related to that.
Becky Strong - Great. And I think this is kind of a follow up question to that as well, can pemphigoid be active within my eye, without obvious symptoms?

Dr. Djalilian: If the eyes look very quiet, white looking, no symptoms really, very comfortable, it's unlikely that there's disease there. Or let's say a patient comes to me and says, I have no symptoms and my eyes are white and quiet and when I look I see some scarring. I'm not going to treat it because I say you don't have any active inflammation, there's nothing to treat. But the second part of that question, to prevent it from spreading to the eyes. I would say avoid things that can irritate the eyes. Like I said, they are on chronic drops. Or some patients have asked me this, they wear contact lenses, could this chronic contact lens wear also contribute to the eye involvement? I'll say, maybe, but not sure. I can't say it for sure, but certainly anything that the patient is doing such as wearing contact lenses that are irritating the eyes, that by the end of the day the eyes are very tired and red, then I would say, maybe your eyes are telling you that they don't really like what you're doing, whether it is contact lens wear or something else. Same thing, as part of our job we're on a screen all day long, and at the end of the day the eyes are very red and tired, that's not something you want to do regularly. You want to be able to break that cycle otherwise that could potentially contribute to more disease activity on the surface of the eye. So having more breaks, using artificial tears, things like that can help.

Becky Strong: Interesting, I never thought about looking at the screens could make the disease worse. That's a really interesting point with so many of us working.

Dr. Djalilian: Especially at the end of the day, if we're feeling it. I know for myself if I have a big project that I have to work on, and I'm on a screen for 7 or 8 hours straight with minimal breaks, at the end of the day my eyes are screaming for help. They don't want me to to continue

Becky Strong - Absolutely. I know we talked about the seriousness of eye symptoms and scaring and things like that. But how quickly can blindness occur?

Dr. Djalilian: Yeah, fortunately not quickly. I would say in most patients, the most common reason for blindness is delayed diagnosis. That's almost always the case that it wasn't recognized early enough. If it gets recognized early it's very treatable and it's very rare that someone would go blind if they were diagnosed early on and were treated.

Becky Strong - Great. I think we've answered the next couple of questions, we've talked about dry eyes. There was a question, though, at the bottom. I'm sorry. Karen asks, when treatments such as IVIg or Rituximab are stopped, what's the probability of relapse in the eye? And how soon is this likely to happen?

Dr. Djalilian: Yeah, good question. It definitely can happen. I've certainly seen patients who go through treatment, let's say for 6 months or year, and then we say, let's go ahead and try to see if we can gradually spread out the IVIg, or just stop it and see. But then within months,
again, there are other external factors that are involved in triggering the disease that we don't completely understand, but it certainly can happen. And I would say it would be within the first 6 months of stopping it. They'll start to feel their symptoms are coming back, or redness, or whatever.

**Becky Strong** - Great. There's a couple questions in the comments when we were talking about the eyelashes turning in. Robbie has mentioned that sometimes she'll tape the eyelashes to her face so they're not bothersome, with face tape. Is this an okay practice, or should something else be done instead?

**Dr. Djalilian**: I think it sounds fine, as a temporary measure, but I would I mean I would be more in favor of them seeing someone to help. So anything related to eyelashes that's more definitive has to be done by an eyelid specialist, what we call oculoplastic. So I would be in favor of them seeing an eyelid specialist, especially if the disease is under control. They may be able to do things so they don't have to do that. But I mean certainly, in the absence of anything else I don't see anything wrong with that practice. But I would hope that they can find more definitive treatments, so they don't have to do that.

**Becky Strong**: Great, Elizabeth asks an interesting question in the comments as well. Do you see a difference in eye dryness in postmenopausal women or women who have undergone an inferectomy and are not using hormone replacement therapy?

**Dr. Djalilian**: Yeah, that's a great question. Definitely hormones are for sure tied into it. Our experiences show epidemiologic evidence that dryness of the eyes are more common in females and also become more common in postmenopausal women. We know that hormones are tied into it. But I don't know if it's as simple as just saying, oh if you just have this hormone, then you'll be fine. But for sure that has been shown.

**Becky Strong** - Great information. Our next question that was pre-submitted, Edward says 8 years ago the disease caused him to have a laceration on his lower lid. He's tried various treatments, including drops and ointments but, however, it has not resolved. Are there any procedures that could help with a laceration on the eyelid, like the one he has?

**Dr. Djalilian**: I am not sure what he means by laceration. I'm wondering if he means scarring, because it's likely there's a scar. You can see in some of those pictures a band of scarring that develops in those areas. Unless the scarring is causing a lot of turning of the eyelid and causing a lot of problems with the lashes then that's a problem. But just because it's a scar there, and if it's quiet and it's not progressing that's okay to just observe it. Because it's unlikely for a laceration to go on for 8 years and not heal. I really think it's more of a scarring. As long as the disease is controlled and the scarring is not progressing, then nothing really needs to be done. The only way to fix it, you can fix it surgically but I wouldn't recommend it if it's not causing any problems.

**Becky Strong**: Great. This next one is probably a little bit complicated, but if a patient has never had symptoms of red eyes, but the OCP is progressing as seen by symblepharon involvement, at what point is it advisable to start taking Rituximab?
**Dr. Djalilian:** This is a very, very good question. So there are some patients that it seems like when we look at the eyes they seem they're okay, we don't see any obvious signs of inflammation but they could still develop scarring. And if the scarring is progressing, let's say someone saw this person and there was no scarring and then six months or a year later and there is new scarring there that was definitely not there. And during this time the eyes were not inflamed then that is a sign there is subclinical activity, meaning that the disease is active but it is not so active that we can actually see it as red eyes. So the level of inflammation that is not visible to us but there must be inflammation there. I've certainly seen patients like that. In those patients, I think Rituximab is definitely overkill for sure, because that patient does not have highly active disease. I would start probably more with these oral agents, something more simple as doxycycline or minocycline, then maybe mycophenolate. That may be more appropriate and safer for the patients. Then only if they are continuing to progress on those medications would I go to Rituximab.

**Becky Strong:** Great. How should the ophthalmologist and dermatologist keep track of progression of OCP?

**Dr. Djalilian:** For the dermatologist it's very hard, but ophthalmologists can. And really the way to document it is basically you have to document the level of scarring and this is best done by either documenting the chart, let's say a scar was noted in this part of the eyelid. But even better is with photographs. With patients, in the office we'll take photographs, or the patients themselves could also even photograph their own eyes by pulling the eyelids down, looking up, sort of documenting the amount of scarring that there is. Same thing with the upper lids and then if you see a change where previously there was no scar, and now there is a scar, that's a sign of progression. But ophthalmologists do this in the office usually, they'll document where the scar is and monitor it over time. But for dermatologists is harder for them to do.

**Becky Strong:** Toby says that she's had pemphigus for 20 plus years, and she put in the comments that she's been in remission at least 12 years and is going to have cataract surgery. Is it preferable to have traditional surgery or laser surgery?

**Dr. Djalilian:** It makes no difference whatsoever. There's no advantage. Both of them should be very safe in a patient like this.

**Becky Strong:** Great, are there any contraindications to having any surgeries of your eye when you do have active disease?

**Dr. Djalilian:** So during active disease, I would say, in general we want to avoid surgery that's elective. So we would delay caterers surgery for instance, that's probably the most common surgery that would be involved. Because anything that triggers inflammation on the surface of the eye could potentially make the disease more active. But again, if it's a surgery that needs to be done, then it's okay we just have to have patients on a higher level of medication to really quiet things down. Let's say if it's an urgent procedure that has to be
performed, then we do it under maybe a higher dose of steroids to keep the eye from getting more inflamed to make sure it quits down quickly after surgery.

**Becky Strong:** Great. Teri just submitted a question about if you could speak to being in the sun and its implications of OCP.

**Dr. Djalilian:** So many patients are light sensitive when they have active eye disease. I would say, I don’t see a problem with them being in the sun unless they're in the sun without any kind of sunglasses for several hours, and they're in the southern part of the U.S. where there's a lot of UV exposure. Then maybe over time, that could have detrimental effects on the surface of the eye. But I don’t see any problem with the eye disease getting worse by being out in the sun. If anything, getting more vitamin D would also be beneficial for their immune system.

**Becky Strong:** I think you kind of started to answer the second question on this slide about, I have dry eyes and light sensitivity, where do I start and how do I care for my eyes? Is there anything else that we should be doing if we have the dry eyes and light sensitivity that you didn't just mention?

**Dr. Djalilian:** Obviously, I think they should be seen by ophthalmologists to make sure that their eyes are okay, and it's just dryness that there's no active disease activity in the eyes. I would say start with lubricants. Another common thing, drinking lots of fluids, staying well hydrated because being dehydrated will also make our eyes more dry. Taking breaks from the screen every half hour, also blink to blink more.

**Becky Strong:** Okay. I think the next 2 questions kind of go together. Why do eyelashes grow inward? And is there anything you can do to prevent this from happening? And how do you protect your eyes while waiting to have your eyelashes removed?

**Dr. Djalilian:** So like we said, it all has to do with the scarring of the inside the lid. So if there's scarring here that pulls this lid inward, this is going to make the lashes turn more inward. Preventing it is just basically, keeping the inflammation controlled, that's all there is to it. The more you can keep inflammation controlled, the less likely this is going to progress. While you have an eyelash that is growing inward and you are waiting to get to someone to remove that eyelash. Ointments, having some kind of ointment on the surface, maybe a little bit better, maybe provide some protection. Keeping the eye closed. Finding someone that will pull the lash for you at home. If the person is a contact lens wearer, having a contact lens in the eye will help protect the eye and reduce their symptoms significantly. Some sort of eye ointment or eye lubricant on the surface of the eye, that will likely help provide some protection and some of them you can get over the counter ointments that might help. Again, it's going to vary from patient to patient what they find helpful. Otherwise just keeping the eyes closed, that may be helpful.

**Becky Strong:** We've gotten a couple questions. I know we've talked about it but if you could reiterate, what can be done to help that gritty feeling and the blurry vision?
**Dr. Djalilian**: Again, that's typically from dryness on the surface of the eye. So I would say, the first thing would be to try to get some lubricant eye drops into the eye. Like I said, the ones without preservatives. Patients also often asked me, so which brands do you say are good? There are many good brands, and I don't have any financial interest in any of them. But some of the more let's say, well known brands are like Systane®, Refresh®, Blink®. These are probably some of the more popular and common brands, and those are all good brands, all available over the counter. Something else that we also have patients do, because there are oil glands in the eyelid, and those oil glands can get inflamed and get plugged so the oil may not flow so easily. Sometimes we have patients use a warm compress. That sometimes helps by allowing more oil to flow onto the surface of the eye and melting that oil that's gotten thick so it flows better on the surface. A lot of patients also find that soothing. Those things you can do on your own, and the rest of these require a physician, and prescription eye drops.

**Becky Strong**: I'll finish the webinar with this one question. When do I know if I need more treatment than the eye drops and if it's time to move to a systemic treatment?

**Dr. Djalilian**: In general, I would say if it is a very mild disease. Then you can get away with drops. It has to be very mild. If the disease is still active, signs of inflammation and redness that we talked about or if there's progression, more scarring, or if the treatment is not controlling their symptoms, then I think it is time to consider something else. I would say, when a patient comes in with active disease we usually will just go straight to systemic. We don't just do topical unless it's very mild, like minimal signs of inflammation or minimal redness.

**Becky Strong**: Great. Well, thank you so much. This has truly been a really educational hour, and I know that our community really appreciates the time that you took joining us today.

**Dr. Djalilian**: My pleasure, definitely happy to answer any follow up questions that come up later.

**Becky Strong**: Great! Before we go, I do have a few announcements. I hope that everybody will join us on Monday, April 8th to discuss skin care with Dr. Benedict Wu, Director of Inpatient Dermatology and Associate Residency Program Director and Assistant Professor in Medicine at Mountefiore-Einstein. Then, on May 21st Dr. Victoria Wu, Director of Pathology at Texas, A&M School of Dentistry will discuss oral disease treatment and care. You can scan the QR code on the screen or go to our website to register. Please be sure to register for each individual webinar that you would like to attend.

**Becky Strong**: If you wanna stay updated about upcoming webinars, events and important news in our community. You can opt into our mailing list. You can join our mailing list by visiting
our website www.pemphigus.org scroll to the bottom of the page and enter your email into the join our email list box.

**Becky Strong:** We’re excited to announce that this year’s Patient Education Conference will be held in person in Newport Beach, California. We hope to see you all there, so we can finally meet in person. The conference will be held October 26th and 27th. So mark your calendars and be on the lookout for more information and more announcements when registration will be open. Space is limited, and we hope to see you in October.

**Becky Strong:** Have you checked out the IPPF’s newest resource, the IPPF guide to Pemphigus and Pemphigoid? This guide is intended to provide medically reviewed information relevant to the most common questions people have when first diagnosed with pemphigus and pemphigoid, as well as educational information about ongoing disease management and treatment options. Through this guide and other IPPF resources we help to help empower the community with essential knowledge that can make living with pemphigus and pemphigoid more bearable.

**Becky Strong:** You can also check out the Find A doctor Directory. You spoke up and we listened. You let us know that the map format just wasn’t working for many of you, and we listened to what you had to say. Now we have a directory style that allows you to search by many criteria to find doctors who, we believe, are familiar with pemphigus and pemphigoid in your area.

**Becky Strong:** Next, you want doctors and researchers to better understand our disease? Do you wish there were more FDA approved treatments and better treatments available? Well, here’s your chance to get involved and make these goals a reality. You can join the IPPF Natural History Study today. The Natural History Study is a patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US. Food and Drug Administration (FDA). Your information is private, and the Natural History Study follows strict government guidelines to ensure patient information is protected. The IPPF will use your participation in the data to help advance research, better understand the patient journey, find better treatments, and hopefully one day a cure. By sharing your journey and answering some questions, you directly affect the future of all of those affected by pemphigus and pemphigoid. So get involved today and join the Natural History Study.

**Becky Strong:** We’d also like to thank everybody in our community for their continued generous support of the IPPF. Your donations help to connect patients with support, resources and disease experts and also raise disease awareness. With your support we also share the patient experience with medical and dental professionals as well as students, advocate at the
government level and promote research. You can scan the QR code on your screen, or visit www.pemphigus.org/donate to donate today. You can ensure our programs are available to all of those who need them today, tomorrow and for years to come. The IPPF also has a number of virtual support groups coming up around the country. If you're interested in attending a meeting, please check the IPPF's event page to register. We're also looking to expand our network. So if you're interested in starting a support group in your region, please contact me Becky Strong at becky@pemphigus.org. It's a lot easier than it sounds to start a support group, and you can connect with others in your area and help to find the support that you're all looking for. As a reminder, this call recording will be sent out with a survey following this webinar. So thank you for joining us. Goodbye.

Becky, but you know, if we have a couple of minutes I'm looking at the chat now, I'm just looking at it. Now, couple of these questions, just because they're not feel bad leaving them unanswered.

**Dr. Djalilian:** Becky? If we have a couple minutes I am looking at the chat now and I want to answer a couple of these questions because I feel bad leaving them unanswered. I'm going to take a couple extra minutes to go through some of these. This attendee is asking about restasis and they're also using Rocklantan® for glaucoma. They still have itching. Rocklantan® is not a gentle drop on the eye, unfortunately, but it's necessary for the glaucoma. The eyes are dry and Rocklantan® is also irritating. What I would recommend to them, go to their glaucoma specialists and see if they can do something called an SLT. It is a relatively gentle procedure that may help them reduce their dependence on the drops.

**Dr. Djalilian:** Okay, let's go to the next one. This patient became anemic on Dapsone. Sorry I don't have good answers for that.

**Dr. Djalilian:** Lipiflow is going to have a temporary effect. It's going to help the patient feel more comfortable for a while but it's not gonna be a long term effect. Amniotic membrane, again a temporary effect. If the surface is really irritated, putting amniotic membrane might help for a while, but it's again not something long term. The person with the cataract surgery, and really 'm not sure this is related to their bullous pemphigoid but it sounds like it's more related to the surgery itself, because that's surgery inside the eye.

**Dr. Djalilian:** Manuka honey, I don't know that that's really helpful. I would be careful with putting that on your eyes.

**Dr. Djalilian:** Pain around the eye. I mean I wouldn't say that's necessarily a sign of active disease in the eyes themselves. For the person with the double vision, only have surgery when the disease is completely controlled for a number of years and there is no doubt that the
disease is basically burned out. Okay. So I answered the questions that I think would be useful. The rest of them we basically talked about.

**Becky Strong:** Great. Thank you for taking that extra time. I really appreciate that Dr. Djalilian.

**Dr. Djalilian:** My pleasure, my pleasure.

**Becky Strong:** Great thanks! Thank you, everybody. Goodbye.