

February 13, 2024 Patient Education Webinar- Mental Health When You Have a Skin Disease

Becky Strong: Welcome everyone. Our webinar is now being recorded. I'm Becky Strong, IPPF, Outreach Director and your host for today's webinar. I'd like to thank you for being on the call with us. 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 and the IPPF reminds you that any information found online or during presentations like this should be discussed with your doctor or healthcare team to determine if it applies to your specific situation". Today we're really excited to have Dr. Steven Daveluy with us to discuss mental health and serious skin disease. Before I hand it over to him, let me introduce you to Dr. Daveluy. Dr. Daveluy is an Associate Professor and Program Director at Wayne State University in Detroit, Michigan. He earned his bachelor's in science from Michigan State University and completed medical school and dermatology residency at Wayne State University. Dr. Daveluy holds special interest in teledermatology, non-invasive skin imaging, skin of color, integrative dermatology and complex medical dermatology including hidradenitis suppurativa. He is active on the American Academy of Dermatology committees including performance measure and data dermatology oversight. He is the past president of the Wayne County Medical Society and Michigan Dermatological Society. He also serves on the board of directors of the Hidradenitis Suppurativa (HS) Foundation and the editorial board for the Journal of American Academy of Dermatology and the Journal of American Academy of Dermatology case reports and is building a growing body of publications of his own. So before we move over and hand things to Dr. Daveluy, I would like to go over a few housekeeping items... (Reviews Housekeeping Slides). Now it's my pleasure to hand things over to Dr. Daveluy.

Dr. Daveluy: Thanks very much, Becky. Thanks everyone for joining. This is a topic that we were just talking about is so important and sort of something we don't talk about enough. So I'm very happy to have this opportunity to share a little with you guys and have a little bit of a conversation about mental health and serious skin disease.

Dr. Daveluy: As a little outline, we'll talk about what is mental health and quality of life, which is a term we sometimes use. Discuss the impact of bullous skin diseases on people's mental health and review some strategies to really optimize your mental health. Then discuss a couple of mind body medicine techniques that you can actually put into practice and use for yourself or share with others.

Dr. Daveluy: I thought we could start by talking about some of the terms so that we're all kind of on the same page and know what we're talking about. You may be familiar with the term autoimmune bullous disease or autoimmune blistering disease. There's a few different diseases that kind of fall into this category that basically are diseases where your immune system attacks your skin and causes blistering and separation of the skin. So there's bullous pemphigoid, cicatricial pemphigoid, pemphigus vulgaris, pemphigus foliaceus, paraneoplastic pemphigus, acquired epidermolysis bullosa, dermatitis herpetiformis and linear IgA bullous dermatosis, which are all very hard to say and big Latin words. So throughout the talk I'll use in a few places the words autoimmune bullous disease. We'll talk about some of the specific ones too, like

bullous pemphigoid or pemphigus. And if at any point I say something and you're like, what was that one again? Don't worry, feel free to ask.

Dr. Daveluy: Switching gears on the other side of that, what is mental health? It's a term we talk about a lot and gets kind of thrown around and it's kind of in trending in everything, but what really is it? So your mental health is a person's condition related to their psychological and emotional wellbeing. It's kind of one of those things that we all kind of know what it is, but hard to put into terms. It's all about how you're doing mentally and how you're feeling mentally.

Dr. Daveluy: One of the interesting things with mental health and mental illness is a societal stigma. Depending where you live in the world, the stigma is different. This study is from the U.S. and it does show that the stigma with mental health is starting to sort of improve. If we kind of think back to maybe our parents, our grandparents, it was sort of, you're not depressed, you just need to get out of the blues, think about something else, pull yourself up by your bootstraps attitude. We're kind of changing that and recognizing that we really need to pay attention to mental health and mental illness. What's interesting across these graphs is you can see, over the years the stigma is sort of doing better and going down from 1996 to 2018, but it is a generational concept. The graph to the far left shows the ages of participants who are answering, and you can see that the stigma with mental health goes up with age. The younger generations are embodying this new idea that we shouldn't be afraid to talk about mental health and mental illness and tell people when we're struggling. Versus like I said, our parents, our grandparents, our great grandparents it was not something that you talked about. It was taboo. It was sort of this concept if you were talking about your mental health, you were crazy. And fortunately we are moving away from that and moving into this era of no, this is a valid part of our lives and we need to talk about it. Stigma is defined as the disgrace that's associated with a situation, a person or quality. It's that stigma that comes along and says, if you have mental illness, you are crazy, there's something wrong with you. So I'm glad that we're moving in a better direction of de-stigmatizing mental health because it just is a great place for us to get to where people can feel more comfortable bringing this up instead of suffering alone and struggling alone.

Dr. Daveluy: There is some research looking at different bullous diseases and the mental health impact. This was an interesting one out of Denmark where they have national healthcare and they have these national registries so they can look at everybody who lives there. This was over 6 million patients. What's really interesting is that they found that people who had a psychiatric illness had almost an 80% increased risk of developing a bullous disease. And the average time between being diagnosed with their mental health illness and the bullous disease was about 14 years. So quite a lag time. What was really interesting is they looked at medications because we know some medications can trigger blistering diseases or cause them. They found that this risk was independent of being treated with medications or not. So we don't really understand what the connection is there, but it'll kind of speak to what we're going to talk about a little bit later, which is this mind-body connection where your mental state can influence your physical health and your physical health can influence your mental health. It's kind of this backward and forward channel that we see. Then in people who had bullous pemphigoid, there was a 37% increase of psychiatric disease with an average of 4.8 years. This, when they tried to factor in medications,

a lot of it was due to some of the medications or at least attributed to the medications. Now I will say when they do these population studies, it's hard because what they do is they compare people who aren't on medication with people who are on medication. In a disease like bullous pemphigoid, just about everybody is being treated with medication. So it's really hard to tease apart and say, this was from your steroids causing mental illness versus well, everybody has to be treated so it's the disease that's doing it and the steroids just didn't stop it from happening. It's kind of interesting and it's good that we're looking at these things.

Dr. Daveluy: This was a bigger study that actually just took a bunch of different studies, 16 studies with over 600,000 patients and put them all together and said, what's the risk of psychiatric disease with bullous pemphigoid? They found that you had 1.77 times the odds of a psychiatric disorder if you had bullous pemphigoid including 2.6 times the odds of schizophrenia. It's interesting because we think of depression and anxiety are the things that in our head are reasonable when you're going through a difficult disease that impacts your daily living. We understand that you might become depressed or you might become anxious and fearful of a flare up. But it's really interesting to see that even schizophrenia was increased. As we're doing more research, we're learning more and more that inflammation actually affects our brain. So there may be these pathways where it's not just that your disease is difficult to deal with and is causing extra stress, but the actual inflammation that it's triggering in your body might affect your mental health and change your brain chemistry. There was a really interesting study where they used some of the drugs we use to treat rheumatoid arthritis and psoriasis, some of the biologic drugs, and they treated people who had depression but didn't have any kind of autoimmune or autoinflammatory disease. A significant number of people improved, which just goes to show that inflammation itself can affect our brain. So having these inflamed states affects not only our body but our brain.

Dr. Daveluy: Then I wanted to talk a little bit about this concept of quality of life. Quality of life is something that we look at a lot when we're doing research and doing studies. It's basically, how does your disease impact your daily life? It looks at things like the symptoms, embarrassment, your ability to do things that you need to do like shopping, home care, your clothing, your social and leisure life, sports, work, relationships, sex, intimacy. And also how treatments impact quality of life because when we talk about quality of life, the disease can have an impact but also your treatments. They can be really inconvenient sometimes or difficult to deal with. There's a lot of studies that look at this quality of life as a separate metric because maybe you aren't going to be diagnosed with depression or anxiety, but that doesn't mean that your disease is not making an impact on your quality of life and impacting your day-to-day living.

Dr. Daveluy: What's interesting is in the European guidelines for treating autoimmune bullous diseases, quality of life got into the guidelines. They officially recommend that physicians should evaluate the impact that the disease is having on quality of life, especially focusing on painful blisters and erosions and open skin and the itch because a lot of our skin diseases have really powerful itch. And that we should take that into account when we're just making treatment decisions. Sometimes because dermatologists, we're a very visual field, we'll look at things and say something like your skin looks so much better, you don't have a lot of involvement on your skin. But this is saying you need to ask people about their quality of life because if their skin

doesn't have a lot of blisters but they're still having a lot of itch, then that could still be having a negative impact and you need to step up your therapy or make an adjustment. It's one of those aspects of, don't just judge a book by its cover, get on the inside a little bit more. They did recommend a few tools that can be used. Some of these may come up with some of the studies we look at. One is called the DLQI, Dermatology Life Quality Index, and that's one that we use quite a bit in dermatology studies. Then there's one that's specific for autoimmune bullous diseases called the ABQOL. Then there's one about itch, the ItchyQOL. Then there's one final one that's the Treatment of Autoimmune Bullous Disease Quality of Life (TABQOL) that looks more at the treatments and how they impact your quality of life. Are you having side effects? Are there risks associated with the treatments? Are they impacting your life? Then as you can see in my orange bubble there, these are in the guidelines, but how often is this really happening? I'll say this is somewhere that we physicians and healthcare providers need to kind of improve, is really asking people more about quality of life. And I'll say some people do a great job of it, but they're asking us to use these tools. If we were in a lecture hall right now and I asked you guys, how many of you have filled out the DLQI form or the ABQOL form, the numbers would be pretty low. I don't want to rag on healthcare providers too much because we're pulled in a lot of directions, we're busy. But sometimes this is more of an informal thing. So you may be saying, I've never filled out that questionnaire but my doctor does ask me, how are you doing? How is your life? Is life better? Can you do the things you want to do? So sometimes it's a little bit more unofficial. The other thing I'll say is that I am kind of excited because as we're advancing in our technology, I think this is going to help us. We are working on technology where maybe when you check in for your appointment, these might pop up in your phone or you might get a text that says, please fill out the DLQI, we want to know this before we put you in your room for your visit so we can factor this into your care. So I think that as we advance and we're able to make things easier to do, it's going to help us out, at least I hope.

Dr. Daveluy: This study looked at quality of life during flares. What they did is they let patients define a flare. So they didn't say a flare is when you are twice as bad as you were before, or whatever. They just said, whatever you consider a flare, tell us about when you're flaring and when you're not flaring. Then they asked them the questions during flares and between flares. They used a slightly different measurement called the Skindex-16, which is another one that's designed for skin disease. Across all the bullous diseases, there was a greater impact on quality of life during flares. Makes sense, when you're flared up, things are worse. You can't do the things you want to do, your pain, your itch, it gets in the way of your life. What was interesting is they also looked at between flares and they found that pemphigoid and dermatitis herpetiformis had a bigger impact between flares compared to pemphigus. The big take home measure there is that even between flares, it's having an impact on quality of life. Which is something for us as physicians to remember because a lot of times we'll talk about flares and we'll sort of use that as a metric of is the treatment working? But we also need to talk about between flares, how are you doing? What is your baseline? And I think that's one of the challenging things about living with a chronic and severe skin disease, is that you kind of get used to your new normal, right? You are not living a normal life where your disease is not impacting you. You just get used to living with your disease and making these adjustments and doing things differently. It's kind of hard because I think we need to have that conversation of like, all right, well we need to maybe

change treatment to be more aggressive to try to improve and get you to actual normal instead of the new normal of this is just how my life is with this disease. They also found that the patient reported severity, are you flaring, are you not flaring, very strongly correlated with quality of life. What that tells me is, even if I don't have this strict definition of what qualifies as a flare, how many new blisters means you're flaring, I can just ask people, are you flaring or are you not flaring because that matches up with quality of life, which is really what I'm trying to improve.

Dr. Daveluy: Mind body Medicine is another thing I'd like to discuss. It's this idea that I kind of mentioned earlier, that your mental state can affect your physical health and your physical health can then feed back to your mental state. I think we think a lot about the side of our physical health impacting our mental health. Such as, when my disease is flared up it's so stressful, it's so difficult, there's so many things I can't do, but it's good to also remember that it goes both ways. So if we can do something about the mental health side of things, it may actually help your physical health. There's actually physiology to explain it. We have things like stress hormones that can go up and down and that can actually impact our physical health and make our disease get worse. A lot of skin diseases, we know that stress is a flare. You go through a stressful period, you have a death of a loved one, your skin disease is going to flare up because your body goes into a more inflammatory state because it is stressed out. So whenever I talk about mind body medicine and mental health with my patients, I'm always sure to say, this doesn't mean I'm not going to treat your disease. I'm not saying there's nothing else we can do. Let's talk about meditation, so you can get over having this disease. That's not what we're talking about. We're talking about, I'm going to treat your disease and I want to get it under control, but there may be times where it flares up and it could cause more stress for you. So let's also talk about ways to prevent that from having a negative impact on you. The basics of mind body medicine are there's a stimulus, something happens and you have emotions or thoughts related to it and it stresses you out. You have a flare up of your disease and that could be the stimulus. The emotions are like, oh, this is so frustrating. I really don't need this right now. I have so much to do, I won't be able to do things. I have to take extra time for wound care, for taking care of things. The pain is going to be bothersome. Then the road kind of splits. At the bottom is the maladaptive, the negative response. The unhealthy response is to then let that send you on a spiral of negative thoughts and negative thinking like, oh my gosh, this disease is never going to let up. It's going to ruin my whole life. I can never do anything fun. I should just give up and stop planning to go on vacation or to do anything fun because my disease is just going to completely control my life. That increases your stress because that's a new negative stimulus and it creates this feedback loop of just letting the stress spiral and get worse and worse. Then in the blue lines at the top is the adaptive response. Where you go, okay, I'm flared up, this was a very inconvenient time, but I will get through this. I am going to be okay. I can see the light at the end of the tunnel. I will not let this become its own new problem for me. I'm going to relax a little bit and be better equipped to deal with this stress. So that's our goal. It's that things are going to happen that are beyond your control, that's life. So helping to lessen them from having a negative impact is the goal. It's kind of like if you spill your morning coffee, it could ruin your whole day or you could laugh at how funny it is that you spilled your coffee and this could ruin your whole day, but I'm just not going to let it ruin my day. I'm going to move on. I'm going to take a deep breath and it's not the end of the world. I'm going to keep going.

Dr. Daveluy: What kind of things can you do to impact your mental health? Patient support groups are huge and we'll talk about them more. I cannot stress that enough. You're here, so you're already taking a step in the right direction when it comes to patient support groups. Counseling can be helpful, and this could be therapy, it could be a counselor, psychologist, psychiatrist, definitely a good avenue. Mindfulness exercises, which we'll talk about. Then some personal activities that are sort of other things you can do to reduce your stress on your own. And then there's other apps and resources. We live in a great era where there's a lot of resources you can tap into.

Dr. Daveluy: As I said, you're here at an IPPF webinar, so the IPPF can also help you connect with patient support groups. I cannot emphasize how powerful it is connecting with other people who have a serious skin disease and can understand what you're going through. Make you not feel so alone and so isolated. It is truly an amazing thing. Support groups are a huge help and I cannot emphasize enough how powerful they are.

Dr. Daveluy: This study looked at quality of life and support groups and what kind of factors were associated. This was a research project that was in collaboration with the IPPF. They found that impaired quality of life was associated with a few individual characteristics. You were at higher risk if you were female, hispanic, had a history of counseling, which probably speaks to the fact that you've gone through mental health challenges. If you've had the disease for more than three years, it's been weighing on you. Then they looked at what was the impact of support groups. 85% of people who attended support groups said it improved their understanding of their disease. Support group reasons why people went were, increasing their knowledge, meeting other people, getting some resources, and then the guest speakers. I'll note that the guest speakers were the last thing, and I'm super happy it was because I'm here to share some information, but it's not about me. It's about you learning more about your disease, learning tools and resources and then connecting with other people at the support group. Support groups are even better than webinar sessions for it because you actually don't have to just listen to me the whole time, you get to talk to other people.

Dr. Daveluy: Support groups improve people's quality of life, their coping mechanisms, including emotional support. Then, these two ways of focusing on your problems are more on good ways of dealing with and coping with things, humor, family support. They had lower scores for things like denial, avoidance, venting and self blame. Venting is interesting because a little bit of venting about your frustrations can be good, but when you're venting, you are focusing on the negative. So venting is actually sort of a bad coping mechanism because you are just reinforcing to yourself all these negative things and you don't move past them when you're venting.

Dr. Daveluy: Some positive coping strategies for how to deal with challenges are reframing which is sort of like the coffee cup I said earlier. Instead of saying, this ruined my life or ruined my day, you can say, alright, this isn't going to ruin my day. I'm just going to look at it a different way. Humor, sometimes you just have to laugh about it. It's such a terrible thing I'm going through, I can't help but just laugh about it. And then supportive friends and family. Negative coping mechanisms include disengagement where you're avoiding activities, avoiding people

because of your disease. Social isolation, including avoiding dating. Then avoidance in the form of substance abuse and isolation.

Dr. Daveluy: So what are some things you can do? These are some mind body techniques and I broke them down into things that the patient can do and the provider can help with. So the things your provider can help with are hypnosis or this other form of hypnosis called neurolinguistic programming, counseling, that kind of thing. We won't talk too much about those because you can't do those. But under the things that patients can do, there's a long list. Meditation, meditation can be helpful. You're just going to focus on the present moment, let your thoughts go. It breaks you out of those negative thought cycles. Affirmations, which are positive "I" statements. Basically it's kind of what I was saying with venting, if you focus on the positive, there's not room for the negative. So you can say, I'm beautiful in every way. You can do this each morning, you can do it when a negative thought comes in. I'm a valuable person, I'm a beloved family member. It's just a way to kind of put those positive thoughts out there because your brain's going to give negative thoughts such as you're worthless, you're not as good as other people. So you want to block those out with positive ones. Journaling has been proven to help and it kind of doesn't matter what you write about, just writing about things is a way to kind of improve things. It's actually been shown to improve your immune system function. Prayer can be helpful. It's been shown that prayer is most helpful when you are praying in a meditative state. You're really sort of getting into the prayer and it engages some of your relaxation mechanisms in the body. Then biofeedback is something that you may need some help from a provider with. It's a way to sort of calm yourself and you measure your heart rate to show yourself your calming, and it helps to reinforce and teach your body how to do those techniques.

Dr. Daveluy: One of the things that's not necessarily unique but very commonly seen with severe skin diseases is shame. A lot of times it causes embarrassment and shame to have skin disease because people are going to see it. There's two forms of shame. External is how you exist in the mind of others, such as I'm unattractive. It makes you feel attacked by others. People are going to say things about me or look at me. You try to hide and conceal in response and it inhibits your information processing. If you're having a conversation with someone and you're so worried that they're going to notice the blister on your neck, you're not focusing on what they're saying and really engaging in the conversation. That shame is getting in your way. Then internal shame is how you feel about yourself. Self-directed evaluation, I'm not as good as other people, I'm flawed, I'm bad. And it causes you to say these negative things about yourself or think these negative things.

Dr. Daveluy: There's something called compassionate mind training, which is a therapy technique that's been shown to help combat shame. We have two positive systems in our body and in our mind. One is doing and achieving. You work hard for something, you're going for a reward, you get success, and your dopamine gets released and it helps you feel better and excited and energized. Then the other are the social signals. It's different hormones that are released that make you feel better and it's soothing, it's calming. That's what these red pandas are doing in the picture, where the mom is soothing the baby by petting it, stroking it, hugging it. Those things that make you feel good and warm and fuzzy. Both of them can reduce your stress hormone, cortisol, whereas shame and criticism increase your cortisol.

Dr. Daveluy: Compassionate mind training is the idea that you don't need a hug from your grandma to make you feel that sensation and have that effect, you can actually get it from thinking about a hug from your grandma. It's been shown to help in inflammatory bowel disease and arthritis, including reducing the variance in stress by 43%. It is tied to these pro-inflammatory markers in the blood, healthy eating, regular exercise, sleep behavior. So it's a great technique.

Dr. Daveluy: One of the self-compassion exercises you can do is imagine a friend has your disease. How would you respond to your friend when they're saying, I have these blisters, no one will ever love me. I'm worthless. I can't do the things that other people can do. What would you say to them? What would you do? How would you say it? What tone of voice? Now imagine you're struggling and you're thinking those things to yourself. How do you respond to yourself? What do you say? What do you do? What tone of voice would you use? For most of us, it's different. We're much kinder and more helpful to our friends and we're much more critical of ourselves. What leads us to be that way? Why do we treat others differently than ourselves? And what would happen if you responded to yourself in the way you responded to your friend? It's kind of a way to step out and talk to yourself as you would to one of your friends who's going through this, and it helps to just reframe things a little bit.

Dr. Daveluy: Then another thing I wanted to bring up are breathing exercises. Breathing exercises are fantastic. The way I do these in the clinic is if I want to teach someone is, I bring up the idea of mind body medicine like we talked about, and I say these are techniques that can bring your body into a calmer state. Just through breathing you can bring your stress levels down in your body. I might say something like, how does your disease affect your life? What is it preventing you from doing? What will you do when it's gone or it's under control? Then I might say, are you familiar with any techniques or skills to interrupt the stress cycle? Have you tried them? Then sometimes we even talk about this fight or flight, which is your sympathetic and your parasympathetic, which is your rest and digest relaxation. We want to balance between those two.

Dr. Daveluy: Two of my favorite easy breath techniques are the 4, 7, 8 breathing. Where you breathe in, you inhale for a count of four, and it doesn't have to be seconds. I usually use my heartbeat. You can just start to feel your heartbeat. So you breathe in for four, hold for seven and breathe out for eight. This has been shown to engage your parasympathetic nervous system that calms your body down. And a good way to do this, 4, 7, 8 is to do it four cycles two times a day. So in the morning do it four times, in the evening do it four times and then whenever you need it, do it. There's no such thing as too much. You can do it if you're starting to feel stressed and you usually breathe in through your nose, hold for seven and then out through your mouth. We can make our mouth small, which can help us to control the rate that it goes out better. So it's a good way to kind of practice that. I'm going to do the 4, 7, 8 breathing twice a day and then whenever I need it. The more you practice it, you'll get stressed and you'll just do a couple quick breaths of it and all of a sudden you'll feel much calmer. The other is called box breathing, where it looks like a box because the inhale and the holds and the exhale are all the same. One easy example is like a four count where you inhale for four, hold for four, exhale for four, hold for four, and then you repeat inhaling. Just focusing on our breath is a good way to

distract our mind from things. Then controlling our breath, like I said, can control the rest of our body. So these are some quick, easy breathing exercises that you can put into practice right away.

Dr. Daveluy: If you want to do a little bit more, some of the programs out there, there's one called Mindfulness Based Stress Reduction or MBSR. It's an eight week course. You can find it usually if you Google it. You can probably find it somewhere near you that you can do or through this Palouse Mindfulness, it's available free online. Their mission is really to get this out to the masses. I will say it's usually a group activity because there's times where you sort of talk about how it's been affecting your life and what changes you've made or noticed. It is nice if you think you might do this online one, if you can form some sort of group. Even if it's a virtual group with your friends and family or a group at your home, just people around you that want to do it with you. It's nice to have someone to talk to because this one has videos and a manual to go through, but it's nice to have other people that you can connect with while doing it. The other nice thing about the online one is you can adjust your pace. If you only have three days a week, you can give to it, it doesn't need to be an eight week course. You can stretch it out a little bit and kind of adjust things. Then I mentioned compassionate mind training is also available through most psychologists, psychiatrists, mental health centers, compassionate focused therapy, mindfulness, and self compassion. Then there's some brief interventions like the Loving Kindness or the Compassion Meditation. We talked about compassion meditation a little already. Loving Kindness is sort of the same thing. If you Google loving kindness meditation, there are some free ones online. You basically think about love and kindness. A lot of them will have you picture someone who loves you unconditionally no matter what. So for me, it's always my grandma. If I need a booster, I picture my grandma standing there just telling me that she loves everything I do and she couldn't be more proud of me, and she just thinks I am the best thing in the world. That is always the love I got from my grandma, and I just always feel better about myself whenever I do it. I'm like, this is fantastic. I need to be less critical, more compassionate. Yes, maybe I failed at something or I struggle with something, but she's always there like, you are the best.

Dr. Daveluy: Then we live in a great era where there's lots of resources to help us. There's tons of apps that you can use. There are some free apps like Headspace; Health Minds Program; Calm; Stop, Breathe and Think. I personally use Insight Timer. It's a free app where there's lots of free meditations. I love sleep meditations. If you guys haven't checked out sleep meditations, I fall asleep to one every night. They work so well. I've never heard the end of one because you fall asleep in the middle of it. If you want more, if you go to psychiatry.ucsf.edu, they have a whole list of these free apps that have meditation. For some, part of them is free, but you could pay if you want the premium or whatever, we're used to that with apps. It's a really great website to connect to some of these resources and get things that can help you out, help you explore. It's not always a huge commitment. You're not talking about sitting and doing a meditation for an hour. Some of them are a minute, three minutes, five minutes, 10 minutes. So you can kind of build up and find what works for you.

Dr. Daveluy: That's everything I prepared really. I can't emphasize enough that it's really important to focus on your mental health, focus on your wellness, and take a little time for it. It's

something we overlook so much and we neglect in our lives. This was at a great yoga retreat that I was at. They had a photographer there taking pictures and he was like, I got this great picture of you. I was like, thank you. I love this picture. It takes me back to that great time. So just really focus on your mental health, take the time for it. Don't neglect it. Don't be afraid to have conversations with people, especially family members. Then I'm super happy to open up for questions.

Becky Strong: Great. Well, thank you so much. You gave us a lot of really great understandable information, and I sincerely appreciate that. We did get some questions sent to us after. I know you incorporated a lot of the questions that had been sent to us, but we got some others. One of the questions is, what are some good resources for finding a mental health professional near me and how do I determine if we're a good fit?

Dr. Daveluy: So the first part is a little easier. Psychology Today has a listing of mental health professionals that you can go to, and it's a very convenient way to find mental health professionals. The fit part can be a little bit trickier. One of the other challenges with having a serious disease is that sometimes at the beginning of your relationship with your mental health professional, you actually have to teach them about your disease because chances are they have not heard of it. They know a lot about mental health, but they do not know all these crazy skin diseases that people can get and even the names are like, what? But they're usually very willing to learn and they're still equipped with the skills to understand that you have a serious disease that impacts your life and move on from there and kind of learn from you but go on. So don't, don't be surprised if sometimes you have to do a little bit of teaching to the person who's going to be helping you, but usually you'll still get that kind of good vibe. Then don't be afraid if you do need to go, you know what, this isn't working for me. I think I need to move on. I will say sometimes part of the mental health process can be a little challenging. They may challenge some of your beliefs. So don't run away too much if you're like, oh, this is tough. I don't really agree with what they said. Keep an open mind and be there with them. But if you start to feel like it's not a good fit, also don't feel like you're married to that person. You can try someone else. Sometimes too, you can look for in the person's profile on Psychology Today, they'll have their areas of expertise and you can look for someone who's a good fit. Maybe if you are in a same sex relationship, you want someone who understands that a little more and it's not going to be a hurdle you have to get over. Maybe if you're divorced, you want someone who understands that a little bit better. If you're of a certain cultural group, you may want to find someone who kind of understands the culture because especially with mental health, it varies so much culture to culture and the way we handle it and the way we interact with our families. So don't be afraid to kind of try on a few slippers before you find the right one. I use Psychology Today as a good resource for sort of getting the ball rolling and starting things out. Then again, going back to the patient support groups. That can be a great way to be like, this person I've been working with, they understand autoimmune bullous diseases because we've worked together and they know what it's like, talk to them. The cool thing about mental health is that in the era of virtual visits, mental health is perfect for virtual visits. You really, for the most part, don't need to go to their office. So you can do a ton of virtual interactions with mental health professionals. So they don't need to be near you. It kind of gets rid of that distance thing and some are even licensed across state lines where you might be able to see someone in a

different state who another patient recommends to you because they're licensed in both states. It's another good idea to really talk to other patients about, all right, who knows about our disease? You could just get that leg up, that little head start.

Becky Strong: Oh, great. Great information. Are there either counselors or mental health professionals, therapists that specialize in chronic diseases? Will that say that in their bio?

Dr. Daveluy: That's a good question. I'm trying to think if I've seen some who sort of call out specific diseases that they specialize in such as I specialize in diabetic counseling. But I haven't seen too many that just say chronic disease, although now that I say that I've seen some who have chronic illness as one of their areas of expertise that you could sort of look for.

Becky Strong: Great, thank you. Catherine asked, do you think newer doctors are learning more about mental health for non-psychiatric diseases?

Dr. Daveluy: 100%. It's very interesting to see the generational differences where especially the students who are in med school now, especially looking at the ones who trained and started their med school during the pandemic, mental health is just part and parcel to their life. They talked about it, it was a big issue during that time. For these med students, it's like, are you going to be working in the hospitals during the pandemic? So it's much more of a day-to-day part of medicine for younger doctors, which is great. I think it's going to help us to keep advancing and push this idea that it's not something that you don't need to talk to your doctor about. Plus, I think too, for all doctors, we're focusing more on it and there's more research coming about the importance. Like I said, the guidelines have these recommendations about ask about quality of life. I think the whole field is sort of swinging and saying this is an important thing. In all honesty, I'm glad because sometimes you're like, why is this? I always talk about, I had this patient with really bad psoriasis. We got her under control on her medications. She came in with a horrible flare up and I'm going, I'm like, oh, do we need to switch your treatment? And she goes, no, no, no, my mom just passed away. I'm just stressed out. I'm flaring up. I'm going to get through this. We don't need to change anything. And she was totally right, once she got through that grief period and all the stress that came with dealing with the estate and everything, she got back under control. And if it was up to me without talking to her about it, I would've been like, oh, time for the next medication. And she's like, no, no, no, I understand why this is happening. But not everybody has that insight. So now I make sure to ask people, what's going on in your life? When someone's like, I'm going through a divorce right now and it's really horrible. Then I go, well, maybe we need to get through that before we change anything else that we're dealing with because that's probably the reason that you're flared up.

Becky Strong: Great. Laura is asking, does medical insurance cover compassionate training or mental health?

Dr. Daveluy: Some will. Usually when you contact one of those centers that provides it, they'll kind of get that information from you if they deal with insurance or if it's just something that is an out-of-pocket cost. Then they'll check with your insurance. You can always contact your insurance too and say, do you cover compassionate mind training? Sometimes too, the

insurance doesn't really know what you're doing with a mental health professional. They just know that this mental health professional is with us and we do this, and so you just go there and do it. Once in a while, depending where you work, it could even be something that your work offers as a benefit or at a reduced price. Sometimes that can be a good thing too, is to find out if your work has any resources or contracted people that they work with. But it's always a good question to ask when you're reaching out to places that provide mindfulness stress reduction or compassionate mind training is, do you accept insurance? Is this going to be something that's covered? Because in the medical world, we're so used to now checking everything with the insurance because that dictates everything we can do.

Becky Strong: Great, great information. Robert says that he was diagnosed with pemphigus vulgaris approximately, or no, I'm sorry, wrong question. Deborah was saying, when pemphigus is raging I don't have the internal resource to do what I need to do, such as meditation or journaling. How do I motivate when I just want to lay down and distract myself?

Dr. Daveluy: That's a great question. It's interesting because sometimes that self-compassion comes in there. You tell yourself, you know what, it's okay if you don't have the energy to do it today. That is alright. And you don't need extra guilt to say, oh my gosh, I wish I would've done this. I should be doing this. Should is such a tough word, always associated with shame. You should do this, you shouldn't do that. So I think that's part of it, is reframing and saying, yeah, I'm having a bad flare so it's fine that I didn't meditate today or I didn't deal with my app and I'm going to do it on a different day and it's going to be fine. Then sort of learning from the experience too. So you can say, what does help me when I'm having a flare? Like you said, maybe it is a distraction. Maybe you just want to put on trashy reality TV and veg out a little bit and get your mind off it. And giving yourself permission to do that. The things that you do want to avoid are harmful habits if possible. So you don't want to get drunk to avoid dealing with it or do drugs to avoid dealing with it because those can have other harmful effects. But if it's something like a distraction where you're like, all right, I need something to take my mind off of this, that's okay. And that's the beauty of self-compassion and the framework of mindfulness is, you don't need to feel guilty if you have a goal to meditate for 10 minutes every day and some days you don't. You go like, all right, those days it didn't happen. That's okay. That's not the end of the world. And that's one of the reasons compassionate mind training has been shown to help people if they want to diet or eat healthier. You get a lot of those dieters who are on this strict diet, oh, I blew it today. I just give up, I'm just going to eat McDonald's for the rest of the week. Or you could say, yeah, I slipped today, not the end of the world. I can get back on track and get back to eating healthy. It's not all or nothing. It's a good way to sort of build those skills that even when you don't have the energy to do the mindfulness activities, you're still compassionate toward yourself and forgiving of yourself.

Becky Strong: Great, so this one is probably going to hit a little close to home for you. Joyce is asking if you have any encouragement for her who is currently in residency. She's a postgraduate year two and newly diagnosed with a skin disorder and often having to choose work over her mental health.

Dr. Daveluy: That is a very good question. That is one of the things, medical residency is getting better, but we're bad for a culture of put work first, put patients first. Which is a good thing in a lot of ways but it's like they say on the airlines, you've got to put on your own oxygen mask before you help other people because if you choke to death, you can't help anybody else. I will say fortunately, we're getting more awareness of this. The culture is changing where you can talk to your program director and let them know. If you feel comfortable disclosing the disease to them so they kind of are understanding. Sometimes we feel this need to sort of hide our illnesses or our struggles, but when you actually do share them, people at work will be very willing to help out if you need it, to cover for you if things are going on in life that are more difficult or challenging. But it's all about your comfort level, maybe you don't want to disclose that to people at work and that's okay too. There are also a lot of times, I know with our residency program, we provide some resources. If residents want confidential counseling, they can get it and it doesn't go through insurance. It doesn't go through anything where I find out my residents are getting counseling, but it's still there for you. So those resources are available. I guess that would be one thing I would say, is find a way to not put it all on yourself and struggle alone. Find some resource, whether it's a mental health professional or like I said, talking to someone at work like the program director who will keep it confidential to see what you need. Because it is hard to not just put work first and neglect ourselves. And it is okay if sometimes we go through those periods. Sometimes work is really busy and you neglect yourself a little, but then you have to bounce back. The Japanese, I'm going to mess it up, I can't remember the word for it. But they have a word that basically translates into forest walking and it's because they have a culture where you work very hard. So then they will literally take a day or a weekend and go on this retreat where someone just walks you through the forest and you touch trees, hang out in the forest, and be completely in nature. It's this total yin and yang of busy, busy work and work is so busy and stressful that then I totally disconnect and I'm like the opposite. Sometimes if you're really busy at work, you almost need to build that in. This is where I totally disconnect, and maybe it's just like a bubble bath. Maybe it's something simple, a little bit of me time here or there. But I'd say try to find ways so you don't have to put it all on yourself and you have someone that you can share it with.

Becky Strong: That's pretty good general advice for all of us. So thank you. We got another question and I think it's pretty good. I think a lot of us with skin, and I'm sure you see it with HS as well, and people say this to us, are there any good thoughts on dealing with a disease that has no cure when people say, well, you'll get better soon?

Dr. Daveluy: That's a tough one. I think that's one of the extra challenges of having a disease that is rare enough that people don't just know it off the top of their head. Like if you bring up diabetes they know what that is or heart disease. They don't understand it, is that you have to take on the role of a teacher. I think one of the most useful things is to try out some different ways to handle it and figure out what works for you. For some people it's humor. They are sort of that comedian who you're like, oh, it'll get better, and you're like, actually, it really won't. Statistics show that there's a good chance I'm going to struggle with this my whole life and I'm probably not going to find an effective treatment, but that's okay. I appreciate you saying it, and it's kind of like this funny way to do it. Or maybe your way of doing it is to go, well, you know what, it's a tough thing and I'm dealing with it in my own way. I appreciate you saying that and I

appreciate your concern. It is kind of a hard thing, and there's this concept of what's the person's intent and what's their impact. You can let people know and let your emotions be your guide. It is okay if you don't say something in the moment too. It's okay to then reflect on something and go, next time I'm going to say this, or I wish I would've said this. It's okay. We don't always respond in the moment. There's so many times where we're like, oh, I wish I would've thought to say this or that. Then you kind of gauge it. You choose your battles. Sometimes if it's someone that you're making small talk with it's like, oh, thanks, okay, let's talk about something else. But if it's someone that you really care about, those are the people that you kind of disclose to, such as I appreciate you trying to cheer me up, but this is a tough thing and I don't really have a lot of hope right now for what's going to happen with it. I appreciate you being there for me. Then that can kind of change the conversation a little bit too so you kind of choose. If it's a close friend, you might have a deeper conversation. If it's someone that you see once in a while at some event, you're like, okay, thanks.

Becky Strong: Great, thank you. We got a couple of questions, I'm going to kind of combine it and make it a little bit more general. When you feel that you need some help, what is the best way to reach out to a friend or a loved one to say that without it being very intimidating to them or to me?

Dr. Daveluy: That's a really good one. This one, a lot of times, sort of depends on the relationship with your friend. Depending on your comfort level, what you want to do or what you've done in the past, you can kind of gauge it a little bit in terms of how do I interact with this person? This is where sometimes it's nice to clarify. Sometimes you have that friend or that loved one who is the problem solver, and if you bring up a problem, they want to throw out solutions. With those people, I am like, hey I need to, I know I said venting is sometimes bad, but I need to vent a little bit, or I just need a listener right now. Would you be okay if you just listen to what I say? You don't have to offer me any solutions. I just need you to listen. Then usually they're a little bit better. Sometimes you want those solutions. Sometimes you want that sounding board of like, I'm going through a lot, I'm struggling. What can I do? And sometimes it depends on their expertise. If your friend is this great mental health professional, you might go to them and be like, I'm really struggling with this. I will say too, our human nature makes us feel like we don't want to burden other people with our problems, but loved ones and close friends like it. We like helping each other and we like being there for each other. So if you kind of feel like, I'm never going to put this on anybody else, don't be afraid to open up a little bit and to allow people in. It really makes them feel more connected to you in a lot of ways. Now, you don't want to dump on somebody all the time and always be like, help me, help, help me. Sometimes you have to monitor yourself and go, okay, maybe at this point I should talk to a mental health professional who can take this on a little bit more. I want to make sure that most of our relationship is us helping each other, enjoying each other's company, but sometimes I need your support. But on the other extreme is, don't feel like you always have to say, I'm not going to put any burden on my friends. Because your friends really want to help you. Your loved ones want to help you and want to be there for you and want to understand. And sometimes it's okay to give them the permission to be like, I know that you have no idea what I'm going through and that's okay. I just need a hug right now. I just need you to listen right now. I just need you to sit with me right now and watch a movie. It's okay to kind of be a little more vocal with them. I say

this all fully acknowledging that we are not good about talking about our mental health as a society. Like I said, we're getting better, but we're not great about it. So it takes practice. It is kind of awkward at first and it's a little bit of trial and error. It's okay to be super transparent with people and say, I really appreciate you being there for me and helping me when I need you. If it ever gets to be too much, you tell me because I will talk to a counselor. I don't want to overburden you with this and I want you to be honest with me. Just open that communication with them because it is a very delicate balance where you're in a relationship with someone that you want their love and support, but you don't want to overburden them. At the same time, you don't want to bottle everything up and then they're more worried about you. The more you do it, the better you get at it, and it's going to be different with each relationship too.

Becky Strong: Great. So a good follow-up question to this is if you are concerned about someone's mental health, what is the best way to approach it with them? To not make them feel worse or make the situation worse, I guess, too.

Dr. Daveluy: Especially because of that stigma. For example, when I bring it up to a patient in clinic, I often say something like, we know from our research that pemphigus can have a major impact on your mental health. Would it be okay if we talked about your mental health? It gives them that permission. I give them that power to, literally, if they don't want to, they can say, no. I steal a little bit of this from the way I give people feedback on something. Sometimes it's nice to talk about behaviors or actions. So you could say something like, I noticed that you're not coming out as much with our friend group. I just want to check in if everything's okay. I love you and I just want to make sure that I'm not missing anything for you. Or I noticed that you're doing this differently or that differently. That's delicate, you want to bring it up in a non-judgmental way. Sometimes those are those things that are making you feel that way, right? You can say, if everything's fine, just tell me to back off but I notice that you're not coming out with the group as much. Everything, okay? I'm here for you if you want to talk, I'm here. Just want to put that out there. And that can help to put it out there in a non-judgmental way. You don't want to go in and ask, are you depressed? You seem like you're depressed. And depending, if you sort of know someone, if they've disclosed to you before that they have a serious disease or a chronic illness they're dealing with, you can even start with that, like, how's the pemphigoid doing? I haven't asked you about it in a while. And that just opens the conversation and kind of opens that doorway. If they're like, oh, it's flared up. Then you can ask, how are you doing with that? Is that causing you a lot of issues? How is it impacting you? Like I said, it's going to be different with every relationship too, but you'll be surprised. We have this sort of nature of let's not talk about things that are uncomfortable. But sometimes the other person really appreciates you bringing it up and it's very rare that they are sort of upset by it. Even if you don't do a great job bringing it up and you go, oh man, are you depressed? You seem down. They might still be like, no, I'm okay, but I appreciate you asking. So it's good to kind of reach out when you feel like you can. And sometimes depending on your relationship with the person, you can even be like, hey, do you want a hug? I don't know, I'm getting a vibe that you need a hug today. And then that might start the conversation.

Becky Strong: Great tips. There's an interesting question. Are there any studies that have shown that the patient reported quality of life scores and what the doctors are seeing and

evaluating, are they equal? Or are patients feelings things more than the doctors are realizing? Is there any research on that angle of things?

Dr. Daveluy: There is, and it's very interesting. So there's some studies, they are sort of quality of life, but sort of just disease overall. They ask the doctors, what are the important things? What shows you if the disease is doing bad or doing good? And then they ask patients and they often don't line up. So there's a real classic one from psoriasis where the doctor goes, well, I look at their skin and the skin clearance is the most important thing that tells us how treatment's working. Patients said it was itch and skin clearance was second. They kind of don't care if they still have a little psoriasis on their skin. They care about the itch. It's been kind of eye opening as some of that research has come out that really says, you need to talk to your patients about how they're doing and how things are going. It's kind of funny because as a doctor if I have those conversations, sometimes the funniest things come up of what is important to you. Sometimes I'll ask patients, what's your treatment goal? How are you really going to know if this is working? One patient with psoriasis who was flaking a lot and his wife was with them and she said, I'm going to know it's working when I don't have to vacuum every day. That means that your treatment is working. He's not flaking all over the house. A patient with HS who had drainage a lot from their buttocks said, to me, treatment success would mean I can sit on other people's couches without putting a towel down. It might be something like, treatment success to me means I can look at anything on the menu and order it without worrying how it's going to feel going down my throat and if it's going to hurt going down my throat. I love asking that question because I feel like as a doctor it gives me a little bit more of a human connection, what's really important to you in your life. But like I said, our research shows that we tend to look for some of the things that maybe a clinical trial says, such as the amount that percentage of your skin that's involved with your disease is how we know if the treatment's working or not. But even in clinical trials, they're starting to include these patient reported outcomes, these quality of life measures. I think those are the really impactful things when I'm talking to a patient about starting a medication and they go, well, how well does it work? And I go, this is how well it works, but it also works this well for quality of life, or quality of sleep, for pain, for itch. So it is one of those things that we're talking more and more with doctors about. That you can't just go by things, you've got to ask because maybe even if someone's skin is clear, they're still having a lot of itch and they're still miserable.

Becky Strong: Great, yes as you were talking and you were mentioning about eating anything on the menu, I remember the day that I could drink from a straw and my lip didn't stick to it and that was a big thing. So all of that is great. Thank you. One last question, and I think it's a good one that may help a lot of people in our community. David is asking how to take care of your mental health when your partner's very serious conditions themselves outweigh yours?

Dr. Daveluy: Oh, that is a really tough one. And it's a challenge because you want to be there for them but at the same time it kind of goes back to that, put on your own oxygen mask first. If you give too much to your partner that it starts sort of harming you or putting your own feelings behind too much, that can be a real challenge. Sometimes, that is one where I definitely think getting a mental health professional's help can be really useful because it's a balance, right? You're going to have to find, how much can I give but still have enough to take care of myself

and to still be okay? Because the difficult thing is if you give too much, then you're not going to be able to give more, and you're going to start to be less successful in helping your partner deal with their illness because you yourself are going to start struggling and you're going to not be able have the capacity and that backup reserve to really give those emotions. The other thing too is there's this concept of respite care. We really talk about it a lot when someone is a caregiver for a loved one, is that sometimes you need a break. That's another way that it can be helpful too. You may need to talk to a mental health professional and so may your partner who's dealing with this illness. And maybe it's even couples therapy together to sort of say, hey, we both have this serious illness and we need to figure out how to navigate our relationship so this doesn't have a negative impact on either one of us. Then like I said, that respite care, it might come in the form of some time away, someone else to sort of share some of the burden, whether that be a mental health professional, another loved one, or an outlet for you to find your joy and get a little break from being a caregiver and just giving all the time. It's really finding that balance. Don't be afraid to reach out to professionals and talk about it. And talk to your partner about it too because like I said, we love to take care of people and to give our love, and other people really love to receive it, but at the same time they don't want to be a burden. So don't be afraid to speak up if you are saying, hey I'm struggling. This is a lot. I'm flared up. You're flared up. This is a lot for us both to deal with. I'm going through it a little bit too, and they may just come back and be like, oh my gosh, me too. Let's figure something out here.

Becky Strong: Great, I'm going to give a little plug too for the Caregiver Action Network. That is a really great organization. They have what they refer to as a toolbox, and it has tips and tricks and a lot of different resources and a live chat. So if you're struggling, that might be a good place to check out too. Dr. Daveluy thank you for all of the great information that you've given us today. I cannot believe how quickly that hour went, but I sincerely appreciate everybody joining us today, and I hope we can all better understand the importance of caring for our mental health. And Dr. Daveluy, I really thank you for all of the prep and the information that you're sharing with our community. So thank you.

Dr. Daveluy: Oh, thanks for having me. And thank you guys all for taking the time to focus on your mental health.

Becky Strong: Absolutely. So before I go, I do have a few announcements for us. We hope you join us for our next webinar on February 21st, where Carly Flumer, a patient advocate, will discuss "Narrating Your Story: Advocating with a Rare Disease". You can scan the QR code on the screen or go to our website to register for the webinar.

Becky Strong: Next, 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 hope to empower the community with essential knowledge that can make living with pemphigus and pemphigoid more bearable.

Becky Strong: Do you want doctors and researchers to understand our disease better? 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 your patient information is protected. The IPPF will use your participation and 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 affect the future of all people affected by pemphigus and pemphigoid. So get involved today and visit www.iamrare.org or scan the QR code and join today.

Becky Strong: We'd also like to thank everyone in our community for their continued generous support of the IPPF. Your donations help to connect patients with support, resources, disease experts, and to help raise awareness. With your support we also share the patient experience with medical and dental students and professionals, advocate at the government level and promote research. 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 that need them today, tomorrow and for years to come.

The IPPF also has a number of virtual support groups across the country. If you're interested in attending a meeting, please click the IPPF'S event page to register. We also are looking to expand our support network. So if you're interested in starting a peer support group in your area, 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 help connect to others in your area to find the peer support that everyone looks for. This call recording will be sent out with a survey following this call. Thank you all for joining us. Goodnight.