March 23, 2026 Patient Education Webinar- Mental Health

Marc Yale: Welcome everyone. I'm Marc Yale, the IPPF Research and Policy Advisor and I'm so glad that you're joining us today. But before we get started, just a quick reminder that this webinar is now being recorded. We also want to remind you that information is essential when it comes to managing and living with any condition, but remember everyone's journey is unique. The IPPF encourages you to always check with your doctor or healthcare team to make sure the information you hear today or that you find online applies specifically to you and your situation. Today we're excited to have Dr. Marni White with us to discuss mental health support in blistering diseases. Why, when, what, and how to find it. But before we get started, I'm going to launch a poll with a few icebreaker questions. And if you'll take a moment just to answer those questions, we would greatly appreciate it.

(01:10)
There are four poll questions. Please answer all of the questions so that we can better understand your experience with your disease and how you may be affected by mental health.

(01:23)
And while we are answering those questions, I do have a few housekeeping announcements to make. So before we get started, just a quick reminder that everyone will be in listen mode today during the webinar. And if you are joining on a computer, you can listen in either through your computer speakers or by calling in on your phone. To choose your audio option, just click the little upward arrow next to the audio settings in the bottom left hand corner of your screen. And from there you can select your preferred method of listening today, whether that is computer audio or telephone. And do make sure to pick the one that you plan to use today and the one that works best for you.

(02:12)
If you'd like to ask a question today, just click the Q&A button at the bottom of your screen and type your question into the text box. You're welcome to submit questions at any time during the webinar and we will do our best to answer as many questions as possible in the hour. Please remember on today's webinar that we will be discussing mental health support. So if your question falls outside of the focus of today's session, I may ask you to reach out to me by email after the webinar so we can follow up with you. Also, for those of you that are on listen mode only on your phone, please note that you will not be able to submit questions live. However, you can still submit those questions to the IPPF on the IPPF website. To take part in the QA today, simply click the link in your confirmation email to join via your computer or device.

(03:11)
So I'm now going to share the results of our icebreaker poll so you can see who we have on the webinar today and who's with us. So we've got a wide variety of people on the webinar today, anywhere from six months to a year. We've got people that have had the disease, more than seven years, some caregivers. And then of course great results on some, looks like for the most part, a lot of people have sought mental health support, which is great. I'm sure Marnie's happy to hear that. And anxiety, pain, visible skin and oral symptoms. Obviously these are all things

very important and everyone's affected by these. So great. Well, thank you everyone for taking the poll. We definitely appreciate it. So I'd like to now introduce you to our guest speaker today, Dr. Marnie White. And Dr. White is a US-based clinical psychologist and epidemiologist and professor of psychiatry and school of social behavioral sciences at Yale University.

(04:29)
Much of her research and clinical focus has been in eating disorders, body image, depression and anxiety. She has recently expanded her research to study the psychosocial consequences of living with autoimmune blistering diseases like pemphigus and pemphigoid and also other severe skin diseases. And she aims to extend her clinical research expertise to this community by developing mental health supports for individuals living with autoimmune bullous diseases. So I'm very excited to have you here today, Dr. White. Thank you so much for being with us and thank you for joining. And I'm going to hand it over to you and after your presentation we'll take some questions. So over to you, Dr. White.

Speaker 2 (05:16):

Thank you so much. Thanks, Marc. Thank you for that really nice introduction and mostly for inviting me to be here today at all. This is a topic that is very dear to my heart for a variety of reasons, primarily because obviously I've devoted my life and career to trying to help people with various mental health and physical health challenges and also because I'm a patient living with pemphigus vulgaris. And it was because of this community, the IPPF and participating in some of the online support groups that I came to realize that I need to pivot my research and professional focus to try to help people with navigating blistering diseases specifically around mental wellbeing. So for the past few years, my colleagues at Yale in collaboration with the IPPF have been trying to better understand the psychological aftermath of living with a serious blistering disease. So we know that some work has documented negative mental health outcomes, especially depression and anxiety.

(06:25)
And we wanted to better understand and document, document and disseminate to dermatologists and treating physicians really what it is like to live with these diseases. We've learned that there are a lot of disease-specific factors that contribute to diminished mental health. For example, patients report embarrassment and shame around the blistering or about having a serious chronic disease at all. This then can contribute to anxiety and depression, which may lead to social withdrawal and isolation. Another factor is the public's limited understanding of rare diseases and that can manifest as discrimination and invalidation, which leaves people living with these diseases quite vulnerable to negative mental health outcomes. And in some cases, the treatments themselves can contribute to the exacerbation or worsening of depression and mood disorders specifically. Also, the treatments can contribute to significant weight gain and facial disfigurement. And then finally, just the chronic nature of these diseases, the ups and downs, the highs and lows can really contribute to a psychological burden.

(07:45)
It's this cycle of blistering and then going through pretty radical treatments that might make you

feel sick and then wound healing and then recurrence potentially. All of these things in this ongoing cycle can be quite taxing on our emotional resilience.

(08:02)
Okay. Thank you very much. Everyone who submitted questions in advance of this talk that gave me really good insights into what's most important to hear and to tell you about today. Someone submitted this question, how common are anxiety and depression and people living with blistering disease? And so we actually had done some research, again, in collaboration with the IPPF where we sent out a survey a few years ago asking the community to report on a variety of psychological outcomes, including history of any kind of mental diagnosis, not necessarily treatment, but whether or not people had been diagnosed with broad category mental health disorders. And so I want to show you those data. What we have here, these are general population estimates of lifetime rates of mental disorders. And so you can see here we're really talking about for across the lifetime in the general population, nearly 50% of people have been diagnosed with a mental health condition.

(09:05)
So we wanted to look at autoimmune blistering disease prior to diagnosis. And what we found was that people living with autoimmune blistering diseases were either equivalent to or even reported in some cases a lower incidence of broad category mental disorder as compared to the general population. So it seems as though we're not talking about some preexisting psychological vulnerability. However, when we look at following diagnosis, we're seeing skyrocketing rates of depression, PTSD, anxiety disorder, and increasing eating disorder as well, which is actually kind of what got me interested in this because I was wondering what would happen following high dose steroids if people would experience issues with their weight or eating. And also when we're talking about mouth wounds and pain, given that this is my area of expertise, I was very intrigued. And what we found was actually quite surprising and in some ways disheartening, but it makes a lot of sense when we think about the things that can contribute to onset of mental disorders and those things, having severe pain, having a severe chronic disease and all of the things that I showed you on the previous slide, it makes sense that the convergence of all these factors might contribute to the onset of diagnosable mental disorder.

(10:31)
Okay. Some additional questions that you all submitted. These are very important questions and I group them together because I'm seeing some themes. And just to start right out, yes, it is completely normal that feelings of anxiety and depression emerge in or a natural response to severe chronic illness. And as you probably know, in rare diseases, there's not an abundance of research just because it's very difficult to find sufficient patient groups at the same stage of disease to draw statistically relevant conclusions. We can take a lot of information though from research that's been done in other serious chronic diseases, things like cancer, rheumatoid arthritis, multiple sclerosis, and others. And in those diseases, we have learned that there is very direct associations between severity of disease, disease onset and these mental consequences. And so what I want to do is provide a little bit of education around what we

would consider to be a clinically significant threshold for experiencing sadness and anxiety and depression.

(11:48)
And so this is how depression is actually defined. We think of it in multiple domains, affect or mood, behavior and cognition, thinking and types of thoughts, and also the ability to think clearly. And so what we know is that in depression or how we define depression, it's evidenced obviously by sad mood and typically persisting for at least two weeks. You also see anxiety in depression, feelings of hopelessness and also a change in thinking patterns, difficulty concentrating, thoughts of death or dying or suicidality. And then we also see some behavioral markers, appetite changes, either more or less sleep changes, again, either more or less sleep and just diminished ability to function as one once did. Similarly, for anxiety, we see also changes in multiple domains, difficulty concentrating again, also focusing on worry or inability to shift or feel like you can manage these thoughts of worry or catastrophe.

(13:04)
On the physical side, you might see pains, muscle tension, restlessness, again, fatigue showing up. And then you might also see this behavioral domain of avoiding particular triggers or places that might be anxiety provoking. You could also see repetitive checking behavior. And we also actually think of worry as being a type of behavior itself, and so feeling as though that can't be controlled. So these feelings are normal. They're part of the human experience. Everyone experiences feelings of depression and anxiety at times. What we consider to be actually clinically significant is when these symptoms interfere with one's ability to function either socially or occupationally in their job or school. And so this interference happens when people start arguing a lot with their support groups, with their family, not able to work experiencing disability in that domain. And so that's the threshold where we consider something to be of clinical significance, meaning that it might be at a diagnostic level or it might warrant clinical attention, it might warrant psychotherapy or medication.

(14:22)
Now the point that I think is really important to make is that this threshold for what we would consider to be clinically significant might be different in chronic disease, meaning it might be a lot lower because we're talking about very complicated medical regimens. We're talking about a set of factors that's really a lot to bear and that we don't necessarily just as people navigating life get much lesson in the way of how to manage a severe chronic disease and all of the burdens that that brings to the table.

(15:00)
Now, of course, here's my message. Why I think mental health support really matters in chronic disease. Someone asked how patients can manage this emotional impact. We know that chronic disease, any chronic disease, and we're learning in autoimmune blistering disease specifically that having this disease can contribute significantly to one's psychological wellbeing. There's a vast amount of research also showing that stress, the stress of having a severe autoimmune disease can affect the immune response. So we also know that this is bidirectional, meaning that mental health can influence physical health and especially relevant for us today,

physical health can affect emotional and mental wellbeing. Now we've learned from cancer research that psychological treatment can help with disease course. And I'm actually going to elaborate on a few of these studies and I'm really learning a lot and advocating in this space based on really the abundance of research that's been done with cancer patients over the past several decades now.

(16:09)
And we're trying to extrapolate this and understand more with respect to autoimmune blistering disease. And so what we've learned in cancer, a variety of types of cancers, but also chronic health heart disease is that stress management interventions can improve psychological function and quality of life. So that's really promising so that we can have these kind of standardized treatments to help with stress management and they work, so that's great. We've also learned, however, that psychological intervention, specifically cognitive behavioral therapy, and I'm going to tell you more about CBT, kind of behavioral therapy, CBT, is very, very helpful. So in these randomized controlled trials, they evaluated patients who were actively being treated for breast cancer and randomized some to a typical kind of treatment as usual with a variety of assessments before and after. And then others were randomized to this treatment package of a talk therapy, cognitive behavioral therapy, which was focused on helping people manage stress, looking at improving moods, and then also boosting adherence to the medical recommendations and generally working on a variety of health behaviors.

(17:25)
And what they learned is that in those patients who have been randomized to the psychological support, they saw a reduced risk of recurrence, risk of death, and reduced risk of cancer or death from all causes.

(17:42)
And this has been replicated over and over. It's been tested in a variety of cancers. We know now this is really the gold standard. And in fact, in many systems, in many hospital systems now, when people are diagnosed with cancer, they are immediately referred to mental health supports and it is recommended that they enroll in these kind of ongoing psychological, psychosocial support networks. So what this means, obviously I'm suggesting that people pursue therapy for a variety of reasons, but there are particular types that you would want to look for. And the primary goal would be to look for assistance in navigating severe chronic disease because there are a lot of different factors that behavioral medicine and health psychology specific psychotherapy might differ from the general type of psychotherapy. And the reality is patients navigating these diseases have a lot going on and this can fluctuate from month to month, from year to year.

(18:57)
And so I would recommend trying to find a cognitive behavioral psychotherapy or psychotherapist who knows something about chronic disease so that if any of these individual needs, which of course differ for everyone, but if they should show up, the person, the clinician would be equipped to pull from existing treatment modules or if you can think of it as being analogous to a general practitioner who would treat what ails you when you go in for a physical

and they might recommend one medication for congestion or a different medication for high blood pressure. The same applies here. And so you would want someone who's well versed in chronic illness so that they would know to go to the existing treatments and to work with you to figure out what would be most effective or most needed, your priorities, and then also what would be the effective empirically supported treatments.

(19:57)
And I'm going to tell you more about all of that. I'm also seeing a couple of chats coming in, which is awesome. I can't read them right now because I'm sharing screen, but hopefully I will reserve time at the end to hopefully address some of these questions. Okay. I want to give a little bit of education about the types of mental health providers. On the pure talk therapy side, the key thing that I want, it doesn't matter if you're going to a social worker, a counselor, a psychologist, my wish for you is that you just find someone who is well-prepared or at least curious and humble enough to get themselves well-prepared in understanding chronic disease. So it could be counseling psychologists. All of these people on the left, if they are practicing, are required to have a license. And unfortunately in the mental health space right now, I don't know if it's influencer culture or what is going on, but there are a lot of people out there claiming to be mental health providers or experts and they don't carry licenses.

(21:09)
So please, if you're looking for someone, make sure that they carry a license because that indicates graduate training, supervision, licensing exams, regulation by a state board, and generally also carrying insurance, which means they've been vetted. Okay. Where to find therapists? Insurance company provider list would be the first start if you have health insurance and if you are hoping to stay in network, this is very difficult. Just today, I searched my own insurance company to try to find clinicians who specialized in chronic disease and I did not have a great deal of luck doing that. So the next piece would be talk to your physician, see if your dermatologist might recommend someone or your general physician. There are also a variety of major directories where you can search by geography and by specialization. And then if all of these fail, look at Google general search and engines because not all clinicians will be registered with one of these.

(22:21)
I, for example, have a very small private practice and I'm not registered in either of these. I only have a little website and people find me by word of mouth or by searching the internet, but the directories are a really good place to start because a lot of them will also allow you to filter by insurance and type of psychotherapy that they provide. So I want to show you a little bit with the psychology today, you can look by zip code and city and then filter by issues. And then here is an example of what the psychology today website might look like. So you can search just by your zip code and then I would search by in this particular dropdown, whoops, I wanted to search for ... Where am I going? Ah, there we go. I looked at cancer and chronic illness and chronic pain.

(23:09)
Now, of course we know that autoimmune blistering disease is not cancer, but again, I'm

drawing a lot of what we're learning from the model that has been established with cancer research. And when you think about it, we're talking about a severe chronic disease that requires pretty radical treatments and we're looking at similar rates of disability as well. And so I think it is a pretty good model. And the reason I've selected it here is because a clinician who would have expertise in helping people navigate the cancer journey, treatment and ideally recovery would have been trained adequately in what we call behavioral medicine approaches. So that's why I would start and many of these clinicians unfortunately are still based in hospital systems, but if you're lucky enough, I was able to find 13 just in the small town where I live. Okay. Another option, if you are open to teletherapy or virtual treatment, there's something called PSYPACT, which allows licensed clinical psychologists to practice across state lines.

(24:18)
And currently 43 states, if you're in one of these blue states, you might be a candidate for this. And so this basically means if somebody is licensed in Connecticut, they can still treat somebody in Nevada. So that's an option as well. And through PSYPAC, you can also search by specialization. And so here's just an example where they have areas of specialty that you can select and search through those, but I just went ahead and entered cancer here and was able to pull up a bunch of people, 14 people throughout the country, they're all licensed, they're all vetted. They actually have an additional tier of licensing, not only within their state, but they have to do a lot more education and training around how to adequately provide teletherapy services as well. And so these are all people with direct experience helping people through cancer. So I think those are a really good ... It's a particular branch or niche within clinical psychology during training and so on that people are trained specifically to help people navigate chronic disease and all the many factors that come with that, such as pain and relationship issues and so on.

(25:41)
There's another newer option that pulls from the PSYPACT databases and this one does more of an individualized assessment where you would actually meet with representatives and they will match you with therapists based on sort of like a very abbreviated intake questionnaire that you would complete and they will then find you a telehealth therapist. And I like this one specifically because I corresponded with them and said when they sent out notices to would be clinicians and I corresponded with the director there and said, Hey, there's a real need for autoimmune blistering disease. Would you consider adding a search term for chronic disease? And she said, yes, absolutely. That's really important. And so now they do allow that search as well. Okay. These are the relevant specialties. You can try a variety of different terminologies, but you might want to look for chronic pain, disability, behavioral medicine and health psychology.

(26:50)
And then if nothing good comes up, try cancer. Autoimmune does not come up. I tried.

(26:58)
Okay. Again, this is the American Psychological Association locator. Works very much the same way. Here I was able to select chronic illness and health and wellness. The only limiting thing

here is that you would only be able to find doctoral level psychologists. So I mean, sorry, psychology today pulls from a variety, everyone from master's level all the way through to doctoral, but people have to advertise there. So it's not going to catch all clinicians. Similarly here, it's only going to catch those who have registered for it, but it's worth a try because here again, I was able to pull up many people right here locally who had this specialization with complex medical issues. Okay. Things that you might want to look for in a therapist profile insurance match would be a good one. I would want to see what their treatment approach is. I'd want to see that they lean and rely on empirically supported treatments.

(28:06)
This probably will not be on their website that they collaborate with medical providers, but you're going to want someone who is able to communicate and has a good professional rapport with other treatment providers, whether that be psychiatry, medication management, or your physician themselves. You want someone to understand what your goals for treatment are and to be very clear and collaborative in that. I also want to put out a couple of red flags. The biggest one being the licensing. These are all professional safeguards, but also if you're not feeling comfortable with somebody, if you're feeling judged or misunderstood or not heard, if you don't feel that there's a clear treatment direction or if it feels like people are just listening or having a chat, that probably means that's all that's happening. So you want someone to be able to provide some education. So psychoeducation is a very important part of psychotherapy, but you don't want to feel like you're being talked at or lectured to.

(29:17)
And then the other one that I would just be looking for someone who has knowledge of chronic illness or related concerns or is very clearly interested and curious. So no, I haven't heard of that disease. Tell me about it. Can you provide me with information? I will go look that up. I will research that. Okay, here's what I want to know. We can direct them to the IPPF website. We are working on developing some therapist education materials, but we don't have it up and running yet. We're still learning from patients living with these diseases what's most important, but all of this is so that we can build a education supports to boost a mental health clinician network. So things that you might want to ask a therapist just gauge their experience and/or willingness to learn would be my biggest priorities.

(30:20)
Now part of this is, sorry, I'm really passionate about this. I want to make sure that people are accessing treatments that are effective and the Society of Clinical Psychology actually has a website and I've got the address here that provides the tested, tried and true psychotherapies, those that have been evaluated across multiple research groups and have been found to be effective for particular types of broad category mental disorders. Now they haven't done this with physical conditions. They have done it with chronic pain. And you see what I wanted to point out here is that cognitive behavioral therapy, cognitive therapy, acceptance and commitment therapy, which is love it. It's a very narrow type of cognitive behavioral therapy and then again, more of a broad multi-component cognitive behavioral therapy. You can see that time and time again in the case of severe chronic disease, CBT is really winning that race, meaning it's the treatment that works the best for the most people.

(31:32)
And so that's usually an excellent place to start.

(31:36)
Evidence-based therapy approaches for chronic disease and for chronic pain includes CBT, acceptance and commitment therapy, some mindfulness-based therapies, which is also very similar to acceptance and commitment therapy. There are particular modules within ACT that address mindfulness and in some cases, trauma-informed therapy. And so you want people who have experience in applying these approaches. CBT, to give you a little bit of information about what that is, checking time. It views emotions and thoughts and behaviors as being interrelated and cyclical. And the goal is to identify certain types of thinking styles and learn strategies for improving those in a way that are consistent with improved emotion and also behavioral responses. It's a very here and now type of approach. And I know that sometimes what we see in TVs and movies and those kinds of things are you go into psychotherapy and you're laying down on a couch and there's some guy smoking a pipe who doesn't really say anything and is asking you about your dreams.

(32:50)
No, that is not the way this goes. This is very much what's going on, what is stressing you out? Let's work toward problem-solving ways to either view this differently, approach this differently and help you feel better about it. No talking about dreams in CBT unless they're really entertaining, but even then. Sorry, I'm kidding. Okay. Acceptance and commitment therapy.

(33:16)
In ACT, you're developing mindfulness skills to help navigate emotional distress. And the view here is that you're not trying to get rid of emotional distress, that's unrealistic. That's not part of life. It's more about helping you reduce the power of these negative thoughts and emotions over your behavior and your general wellbeing. And it works through building self-awareness, helping you respond more intentionally, clarifying values. And again, it accepts that pain and discomfort are a normal part, but that people can live more fulfilling lives with learning particular types of strategies or skills. The first therapy session, you really wanted to look for fit. All of these credentials and the things and who does which type of therapy are all very important, but really you need to feel important and you need to feel heard.

(34:21)
So you can ask them questions and you should. I love it when people are interviewing me to see whether or not we might be a good therapeutic match and they ask me everything from my training to my attitudes to my thoughts on how social media affects an adolescent's emotional wellbeing. People want to make sure that they are aligned and I think that's great. I think that's important for rapport. Again, my key takeaway, credentials are fine. You want somebody who's licensed, but in terms of whether you're looking for a master's level social work or all the way to a doctoral level psychologist or psychiatrist, it really doesn't matter. As long as they're using one of these empirically supported approaches, I have and would and do frequently refer to and collaborate with master's level clinicians as well. And this is important because not all insurances will cover at a sufficient level depending on degree or credentials of the clinician.

(35:29)
It's the treatment that's most important, not one's training and accolades and diplomas on the wall.

(35:37)
Okay. Another really important question, and this is something that we're just learning about, but someone asking about coping with the fear of disease recurrence. Again, turn to some of the cancer literature on this because this is a concept that has been talked about and understood in thousands of research studies with people navigating and going through cancer treatment and into recovery and remission. We know that in blistering disease, people are reporting fears of disease recurrence at even higher rates or more extreme levels than in people living with many types of cancer. And so this is telling us that we really need empirically supported interventions. Again, in development we're trying. We're not there yet. So I'm drawing from the existing research of what has been done in cancer already. And again, ACT and CBT have helped. This is drawn from an online resource that summarized the existing research on fear of disease recurrence and cancer.

(36:47)
And you can see actually through cancer.org, the American Cancer Society and NCI, many of these websites provide free resources and articles online that can be very, very helpful. What this says in cancer is it's known that this is an issue and it's known that it's hurting patients' wellbeing and quality of life. And so these targeted talk therapy approaches can and do help. People also submitted questions about relationships. Are there any ways to discuss this with friends and family and workplace and then how to help navigate relationships that might very understandably be challenged when you're living with this thing that is really impactful and can be isolating in its own if you feel as though nobody understands it or can relate to it. And unfortunately, I cannot answer these questions. I don't have any blanket advice for this. This is something that I would recommend that someone talk individually with somebody who knows them with a therapist about how to best disclose and primarily how to best elicit the support from one support group that they need.

(38:10)
Some people might want daily check-ins. Some people might be better off pretending nothing ever exists and waiting for specific functional requests like, "Could you please bring me some soup that doesn't burn my mouth versus other people who, can you just sit with me and not ask me about any of this? Can we just have some protected time where we're together and I get to forget about my disease for a little while?" Everyone is going to be different and what's most helpful for them. In terms of how to discuss this with coworkers and boss, again, I don't know. I did, however, want to give a recommendation to please go to the IPPF newsletter quarterly where one of our community members, Kathy, provided a really nice how-to for requesting accommodations. This is highly relevant. You might not want to disclose for a while what's going on with you.

(39:10)
However, the physical condition might require it. And so Kathy gives a whole lot of legal

guidance, but the underlying message here being, here's how to disclose, here's how to handle it and here's what you can do to help navigate your work a litle bit more effectively in a way that will help you improve your quality of life and your work quality of life as well. Someone also asked about body image, and this is something that comes up a lot. And obviously we're talking about skin scarring, skin wounds, and then also those kinds of weight-related issues that I've talked about and really just a radically changing physical appearance. And so it makes a lot of sense that people might experience their body image differently and then it might be distressing. This is, again, something that there is CBT specific to body image. This is a really nice self-help book and I use a lot of Dr. Cash's materials in helping people living with eating disorders.

(40:20)
So it's really helpful tools. I'd recommend it. There's also a website I believe that Cash still maintains, but this is something that you should mention with your therapist and have them do the homework of learning and reading how to do all of this and they can bring the things that would be most specific and helpful to you in treatment.

(40:44)
For caregivers, okay, for caregivers, there's actually even more limited research has focused on caregivers in families with blistering disease, but we do know that caregivers are also feeling it. There's documented impairment and reduced quality of life for people who are caregivers. And the general recommendation at the conclusions of these research articles documenting this are, yes, caregivers likely need support too, either counseling or social support. Again, I'm recommending drawing from existing research in other severe chronic diseases. And what we know there is that caregivers also benefit from group social support from counseling. CBT itself has not really been evaluated here, at least not that I can remember, but I would guess that if I were to search CBT caregiver, I would find evidence of its effectiveness. Did want to point out a couple of online support options. A lot of these, again, come from cancer support, but also for other kinds of cognitive decline like dementia, Alzheimer's and so on.

(42:07)
It exists. It exists and is highly applicable. So these are just a couple. This is supposed to be a national program, but is for some reason got ground to Connecticut because I guess I was Googling from Connecticut and then the Well Spouse Association is one for spousal caregivers. And then also from the 2023, this is on the quarter three newsletter from the IPPF, a really nice discussion for caregivers and talking about how to prevent and deal with caregiver burnout. So I would recommend finding that. Again, that's the IPPF newsletter, quarter three from 2023. Okay. Now this.

(42:56)
Why don't dermatologists know? Well, we're trying. Collaborating again with researchers at Yale, UNC, Buffalo Jacobs Medical School and others. I will say that when I go to these talks at dermatology conferences, I am swarmed afterward by physicians, physician scientists, dermatologists who want to know how to help. At Yale, we're working on developing supports in the clinic, collecting information about mental health in the clinic itself when people are coming to their regularly scheduled appointments so that we can hopefully build in referral networks. I

think that dermatologists know it, feel it, experience it, but don't know the best ways to refer and they want it, but we just don't have it. And we also know in medical management generally, getting mental health screening in your physicals and even the pediatrics is sort of a newer wave that's only been happening in recent years. And so we're hoping to make it standard of care and we're recommending that in our research articles that are going into the dermatology journals as well.

(44:22)
So we're working on it is the point. Thank you. And why do we think there's such a stigma?

(44:30)
I mean, generally we stigmatize things we don't understand and mental health challenges can be viewed as very unpredictable or scary. And so I think that in severe disease, there's an enhanced awareness that yes, navigating life's challenges in the midst of a severe health problem is especially challenging. It's not just one of the things, one of the typical life's bumps in the road. It is by definition very rare, unusual, and therefore unlikely to be very understood. And so I guess my takeaway here is that very few people are born with the coping strategies that help them deal with this sort of thing just as a matter of course. However, people can learn them and develop them and that's where counseling would be an especially valuable tool to help. I think of the counselor as being almost like a teacher who has been studying and learning about the variety of things that can help people going through particular challenges or stressors.

(45:40)
And so the therapist's job is to really canvas and find the tool that's going to be most likely to work for you. And the goal of CBT, as we always explain it, is to teach the client to become their own therapist. It's about teaching and equipping you with skills that you can apply to future stressors as they come up. And then finally, all of this information is possible because of the IPPF's work in advocating and learning and informing and educating clinicians as well as other sorts of population and community groups as well as advocacy and lobbying. For anyone who has participated in the Natural History Study, thank you very much. It helps us learn a lot and it's a longitudinal study, meaning it's looking at people over the course from diagnosis all the way through to remission and ideally cure, but there are some new measures specific to quality of life and how that might interact with a variety of physical presentations as well.

(46:50)
And so if you have not done this, or even if you have in the past few months, there are these very specific quality of life and psychological experiences, surveys that have been added to the battery. So please do consider participating in the natural history study. And that is all I had for today. And I'm ready for questions or to see the chat if any of

(47:14):

That. Thank you so much, Marnie, for a great presentation. You covered a lot of ground. I want to thank you and of course thank everybody again that submitted their questions prior to the webinar today. If you didn't get a chance to submit a question, you can still submit a question on the IPPF website and the Ask A Coach function. So feel free to do that or you can just type it into info@pymphigus.org and we're happy to get all of your questions answered. We also, again, had some great questions that were pre-submitted. We're going to try to get to those today. There were quite a few that were pre-submitted, but we do have some really great questions in the Q&A. And so I want to start with those, Dr. White. And so we had a couple of questions from Celia and Celia says, in my experience, I went or is going through a grief process over my trust over my own body and on the flexibility I used to have in life.

(48:26)
And so she feels a loss of control, which is obviously very common and is having trouble just going for it again, doing things normally. She feels kind of stuck. And so her question is, how do you go about building a new normal life without feeling continuously that you have already failed or that you will not be able to do it and actually achieve what you want to achieve? So that's the question from Celia and I'll let you answer that.

(49:03):
Thank you. Thanks, Celia. I'm sorry to hear this and I think that we can all relate to this. This is something that people have described as body betrayal and you've done everything right, things have been going reasonably well, and then you're really just hit from nowhere by this very severe chronic disease and it is isolating. I mean, the first recommendation would be to give yourself a lot of grace and to try not to pressure yourself to bounce back and get right back to where you were. And so to that end, really trying to view anything as an accomplishment because it is, whether it be being able to get up and take a shower and brush your hair one day, sometimes that might be, well, it might be exhausting, it might contribute to fatigue. And so to give yourself pats on the back for each of these and maybe there's something that's called behavioral activation, it's again, a type of CBT where it's been tested in the context of severe depression where for people who are in that state, even getting up and brushing their teeth might be incredibly challenging.

(50:24)
Now, of course, in our case, getting up and brushing your teeth might also bring a lot of pain and blood and all the things to do with that. And so it's really it's other level when we're talking about a lot of the things like taking a shower or getting dressed might be not only anxiety provoking, but pain provoking. You simply might be physically too physically challenged to do it. And I think that's a really important thing to recognize and give your grace, give yourself grace about of like, just can't do it now. It hurts too much right now. So instead of trying to get up and I don't know what your typical functioning was, let's say it was if you used to work an eight-hour day, try to see if you can do 30 minutes one day and if you can and be sure to applaud yourself and give yourself credit for doing so.

(51:14)
It's hard. It takes a shift. It takes an emotional and a cognitive reevaluation of ... And then also the perspective taking of if you had a friend who was going through this kind of physical issue, this severe disease, and they were sharing with you that they were super fatigued and unable to, whatever they used to do, that was work eight hours, whether it was run a marathon,

whether it was get up and go get the mail at the end of the driveway and now they feel limited in doing it, would you give them a hard time about it or would you say, "You know what? applaud yourself for getting to the front door and opening it or looking out the window."

(51:57):
I really like what you're saying about giving yourself grace, Dr. White. I mean, I know after I was diagnosed, that was really difficult and it's not like something you can ... That happens immediately, You have to learn how to give yourself grace and you have to reframe things and change your frame of mind. So it's not like you could just do that automatically because you were kind of programmed to just do things the way we do things. But I really like what you're saying about that and that takes practice. You have to practice that.

(52:35):
Absolutely. And these are the kinds of things and skills that CBT teaches. And by the way, CBT is not giving me royalties or anything. The reason that I'm pushing it is because it works. If something else were to come along that was even better than CBT, then I would be pushing that. Part of why I chose to go into research primarily instead of clinical practice as my primary job function is because I became very passionate about the need to develop and disseminate effective treatments because I felt like there was so much kind of fluff, hocus-pocus going on that I didn't believe in. And so most of what I've been doing my entire career is actually running these clinical trials and reading others, learning about, for example, the cancer research was really powerful to me. And this was way before I even knew what autoimmune blistering disease was.

(53:30)
I mean, I've been teaching about CBT's outcomes in cancer for many, many years because I think it really speaks to the power that a psychological supportive treatment can do even on physical disease outcomes. And that's why these supports exist in standard care for some of the more common chronic diseases.

Speaker 1 (53:56):

That's a good segue into the next question. And so Becky is asking, how often do I need to meet with my therapist to see real progress? What's your thought on that?

Speaker 2 (54:10):

Most of the work in CBT takes place outside of the therapy room. And there have even been tests of self-care types of approaches where we might run trials of giving patients the treatment manual and they just call and check in for five minutes every week or every other week. It really depends on we'll give homework, for example. The extent to which people engage with that homework and out of session material predicts their improvement. So the standard protocol is once a week for eight weeks. Sometimes it might be once a week for four weeks and then alternating to every two weeks after that. But it's the engagement out of session and the ability if people are able to adhere to the recommendations and do the readings and do the exercises, that's really the more important thing.

Speaker 1 (55:19):

Okay. Well, we got a lot of questions that both today and ones that were submitted prior to the webinar regarding flares. So Celia mentioned it. Christina wants to know how do you cope mentally with the fear of the disease coming back or having a flare or relapse and how do you prevent from not catastrophizing the situation, maybe even becoming panicked or jump to that. You start to go down that rabbit hole and you can think about the worst case scenarios. What are your tips on how to deal with that?

Speaker 2 (56:05):

Again, CBT, we know that in cancer, CBT is very helpful. Celia, what you're describing is so common. We've just started looking at it recently in autoimmune blistering disease and we know that this is a very normal reaction, normal meaning statistically common in patients dealing with this. And the biggest concern is that those fears themselves can contribute to poorer psychological wellbeing. I think it's unrealistic to aim to eliminate them. Of course, if you're having to go and get blood labs every 12 weeks and having to communicate or whatever your protocol is, of course each and every time you have to go in for one of these pretty radical checks and evaluations, you're going to have those concerns. That is normal and natural, but they can be managed. So I don't think that the goal should be to try to control them so much as recognize them, accept them, of course I experienced this, and then figure out new ways to frame them so that they don't contribute to that.

(57:24)
Don't turn the corner into that panic or generally affecting your overall wellbeing. I gave you that slide that summarized all of the resources for fear of disease recurrence for cancer, trying to pull some of those. I can find the actual links to those. I think it was a published paper, but they provided websites as well.

(57:49):
If you can share those with me, then I can share with whoever is curious. And just so everybody knows, the slides will be available. The slides from Marnie's presentation will be available on the IPPF website following the presentation today. Give us a little bit of time to get them uploaded and on there. So you will have the opportunity to review her slides, including the articles. A lot of you were asking about articles from the quarterly from the IPPF website. And if you specifically are looking for those articles, just reach out again to one of us at the IPPF and we can point you in the right direction on where to find those or just share those with you. Dr. White, I know we're coming up on time. This is a really important webinar. I don't know. We've got a lot of questions that we still haven't covered.

(58:41)
I have a few extra minutes. I don't know if you do.

(58:43):
I do. I do. Okay.

(58:45):
Yeah. So I mean, if it's okay with you, maybe we'll go past the top of the hour just because again, this is such an important webinar and such an important topic to talk about our mental health and our wellbeing. We encourage it for those of you online to stay on if you can't, obviously we understand. You will get the recording of the webinar following today's webinar as well. So if you have to drop off, you can obviously watch the last few bits, but I have a few more questions I'd like to ask and then I have a couple announcements at the end. So obviously I know we're going to go over, otherwise we'd have to stop now. So I just thought I would ask you if that would be okay. So we had a question about how can patients tell the difference between normal frustration and clinical depression or anxiety?

(59:40)
How can you tell the difference?

(59:42):
That's- Yeah, that's that occupational or social functioning. When you find yourself arguing with others, blowing up, feeling extreme sensitivity, it's more like this kind of qualitative shift from your normal. And I mean, No. I'm extremely liberal when it comes to encouraging psychotherapy, so I recognize that. I would prefer not to wait until the point of crisis but rather have it be a default. I recommend it to my students. I recommend it to everyone. We go to our physician on regular intervals to get screening, to go and get our blood taken and all these kinds of things to make sure that our physical health is doing well so that we can then apply intervention as needed. And that's very much the medical model. But we ignore that when it comes to psychological and mental and emotional wellbeing. It's only been in the past couple of years, for example, that physicians have during that annual physical asked questions about emotional and wellbeing.

(01:00:57)
I think it should be part of the standard workup. I think that people should get general psychological evaluations. And if there is that signal, try to go into specific treatment for it. I would always prefer to go at the very first sign as opposed to waiting until things are super severe. I think we can think about that with respect to our own physical course. If at that first sore or blister somebody had been able to identify it and get us treated right away, how much better things would've gone overall. Similar thing for psych is to intervene early because we know that that predicts improved course. And this is why in other chronic diseases, when you get that diagnosis and you're meeting with the surgeon and you're meeting to learn about the treatments and you're going through all of the different ... They'll have you walk through going through four or five different treatment providers who are going to specialize through the particular part of your cancer journey.

(01:02:00)
In this case, they also have you meet with a social worker or another psychological treatment

provider right there in the office. You'll have five or six different meetings with the nurse, the physician, the surgeon, and the therapist because it is known you're going to benefit from psychological mental health support for dealing with this. And that's a big takeaway. And I know the dermatologists very strongly believe this, that psychological support would help with the disease course part. So why wouldn't we do that? Why wouldn't we seek that out? I don't care if it's going to be a pill jumping up and down and standing on your head. Give me the thing that's going to help my disease course and to help extend my remission period. I'll do it, in my opinion.

(01:02:44):
Yeah, I mean, I think you're right about the dermatologist. I mean, that's why we're seeing this new rise in the field of psychodermatology. So I don't know if many of you know about this, but there's this new kind of field that is emerging called psychodermatology and the IPPF is very tuned into this new field and the doctors that are starting to societies and doctors that are starting to form groups around psychodermatology, but it goes to exactly what you're talking about. It's not just the dermatologist, but it is that the emotional and the psychological aspects of the disease that lead to better health outcomes. And so it definitely makes a lot of sense. We have a couple other really good questions in the Q&A, so I'm going to just jump to those real quick. This is from an anonymous person, so that's quite all right. They want to know how do you handle mental health setbacks?

(01:03:43)
So sometimes they feel like they're back in control of their life and they don't need to see a therapist anymore and things are going really well. And then something happens and it sets them way back into despair and grief and into that spiral. What's your recommendation on that?

(01:04:03):
The same as before. I'm sorry that you're experiencing this. I think that is also a normal very human experience and it probably will require some shifting of learning kinds of coping skills that you can apply in those moments of like, I've been in this slump before. I was able to get myself out of it previously. Yes, life circumstances are changed and I'm tired of this. These are all natural, human, very real reactions. And so I would even recommend during the times of relative wellness when you're feeling in control and things are going pretty well, maybe that would be a really good time to give yourself some notes. And I almost think of this as a redline technique of when things are going well, live it up, ignore it. You don't have to worry about these kinds of things, but kind of set a little personal check-in for yourself, recognizing that, okay, if I get to the point that I start lashing out or that I'm crying every day or I'm crying twice a week, I don't know, I cry at a McDonald's commercial, so that would not be a very good ... But figure out something that for you would indicate that shift.

(01:05:37)
Where's the point that I can now when I'm feeling good that I know that if I go through this again, that's my mark, that's my signal. So that you've got it there and you've got these outside. I made a promise to myself, I have this threshold and that'll potentially give you the boost that you need in those dark moments to pursue the help that can supportive care. Yeah,

(01:06:00):
That's great. I've got a question. I thought this was a really good question again.

(01:06:04):

So many good questions. Oh my gosh. So many good questions.

(01:06:08):
Yeah. But I was really interested in your thought on this. So the question was, why do you think there is such a stigma around getting support for our mental health? And do you feel that this is changing in society?

(01:06:25):
I do think it's changing in society. I think the stigma comes from multiple levels, including primarily people not knowing, unfortunately just not knowing better, not having adequate education about it. There are certainly some generational effects and some media effects where people believe that any kind of mental disorder or mental suffering is equivalent to dangerousness and so on. And I think that with mental disease as well as all physical disease to some extent, there's stigma due to fear and lack of knowledge. I do think that it's improving and I think that it's improving for a variety of reasons. One, there have been very specific attempts to undo the stigma. There are a lot of really cool organizations that focus on this trying to break down the informational gaps, but also as the field of psychology has moved away from this mother blaming subconscious, unconscious blame early experiences kind of stuff, which is cruel to a more patient-informed, effective clinical trial-based model of actually coming in with deliverable results that have improved people's lives.

(01:08:05)
I think that people are now better able to access care and recognize that it's not a matter of personal weakness, but rather something that should be and is empowering and indicates someone being able to control to the best of their ability.

(01:08:32)
And I always think about this with respect to these diseases specifically and those of you who were at the patient education conference last year, looking at what I know about risk factors for the development of mental diseases, we know there are certain risk factors such as fatigue, financial strain, sleep deprivation, physical discomfort, chronic stress, social isolation. These are all things that can contribute to one's risk threshold for developing a mental or emotional disorder. And these are things that are just the daily experience of living with an autoimmune blistering disease, especially before experiencing any symptom remission. And so when I think about that, if I were evil and wanted to create a mental disorder in someone, I would do it by putting them in pain, making them feel not understood, making them feel not heard, maybe give them a couple of wrong diagnoses for a while, put them on medication that is known to influence mood.

(01:09:43)
I mean, of course people are struggling in the context of this disease. Of course, I'm saying people are as though it's a third person. Of course we are struggling.

(01:09:54):

Yeah. Yeah.

(01:09:56)
It's hard. Yeah, it's very hard. So I have one last question. Again, for those of you who didn't get your questions answered, please submit them on our website, reach out to us. We're happy to get all of your questions answered. We can send them to Dr. White so she can answer them. We can also connect you with a peer coach so they can help you work through some of this. I mean, that's a service that a free service that the IPPF provides as a peer coach, someone that has been living with this disease, understands, has experience and can help you try to work through a lot of the emotional stress and emotional things that accompany this disease. Just a quick shout out to Mary Lou. I know you have your hand raised, Mary Lee, but we're not taking live questions, but I did put my email in the chat.

(01:10:48)
Please feel free to reach out to me. So I've got one last question. Again, we had some really great questions submitted and we will check- Thank you so much. Yeah, we really appreciate it. We could probably be here for hours. And then I've got just a couple of announcements. So my last question to you, Dr. White, is how can, and this is really important because we talk a lot about people living with this disease, but we all know that it doesn't just affect us, it affects our family and it affects our friends and people that are caring for us. So the question is how can caregivers support patients without experiencing the burnout themselves because it's very taxing on caregivers as well. So what's your thought on

Speaker 2 (01:11:37):

That? I would definitely recommend accessing the supports that the Q3 newsletter from 2023 has a section on caregiver burnout and then accessing some of the existing supports that have been established both for spouses. There's something called the Well Spouse Initiative. There are local and national support groups for individuals helping with aging family members and that is not necessarily disease specific. So all of the recommendations that I'm making for patients themselves carry over to caregivers. We know that it's a significant burden and the limited research that has been done has documented psychological and quality of life impairments for caregivers as well. It's really hard. So accessing these supports in the same way and even social support, even just having one other person who's going through something similar can go really far away, accessing those support group networks.

(01:12:47):

Yeah, that's great. And for those of you on the call, just so you know, the IPPF does have information on our website about caregiving. We actually work with a group called the Caregiver

Action Network. So that's one of the other groups that we work with just to try to, again, provide supports for patients or for caregivers that are dealing with patients with chronic diseases like ours. And that's a great resource. So you can find that on our website. If you can't find it, just again, reach out to us. We're happy to point you in the right direction. There is a way where you can actually just type in a search on our website up at the very top. There's a little magnifying glass and you can type that in and look for stuff on our website. So you can actually find a lot of information on our website.

(01:13:32)
You just got to type it in and know what you're looking for. It's kind of like AI nowadays. You have to put in the right question and you'll get the answer that you're looking for. So I want to thank you again, Dr. White. This has been just a really impactful conversation, very important and obviously the time went by very quickly. We had such great questions and we still have a lot more to answer. Thank you. Yeah, thank you so much for joining us today. Thanks all of you that are on the call.

(01:14:07)
We also want to thank everyone for helping us put this webinar together. Before we go, I want to actually launch one last poll if I can. And the poll is if you would just take a moment to answer this last poll. I think it's telling for us and it lets us know whether or not this webinar was useful and how impactful it is. So take a minute just to answer this question. After today's webinar, how do you feel about seeking mental health support? So if you haven't already, so lets us know whether or not, again, this webinar was useful and helpful. Great. It looks like for the most part, people are feeling more confident now about seeing a mental health professional, which that's great.That's what we wanted to hear. So that's wonderful. That's great. We're trying. Yeah,

Speaker 2 (01:15:03):

We're trying. I mean, we don't have it quite yet, but we're trying. We're working and the real dream is to educate clinicians so that more clinicians out there will be able to provide these supports and make the appropriate referrals. And that's the dream we know it's necessary and we have thoughts and even things that we would love to hear from you of what kinds of questions would dermatologists ask? What do you most want your treatment provider to understand? So we'll likely be trying to recruit that kind of formal information too. If you're comfortable putting any of that into an email for Mark or even in the chat here, we would love to hear it. This is what the dermatologists have asked me to ask you all as well.What are the things that have helped you feel heard? What are the most valuable things that a clinician would ask of you or what would you like them to understand about your condition?

(01:16:08)
And then on the other hand, if there have been things that physicians or dermatologists or healthcare providers, including mental health providers have said that have been invalidating, that have really made you feel crummy. We'd like to hear that too because we need those kinds of examples to educate physicians. These are people who want into healthcare for a reason. They want to help, but they're also humans and so they make mistakes, but they want to learn.

They have a genuine interest in being better providers. And so if you can share any of that information, we'd love to hear it. So thank you.

(01:16:46):

Yeah, just to build on that, Marnie, and thank you so much for saying that. I can't stress enough how important it is that all of our voices are being heard. So when we reach out to you, Marnie mentioned the natural history study earlier, we reach out to you via email and ask you to participate in a study that's so that we can ensure that your voice is being heard. It's being heard by the dermatologist, it's being heard by the researchers, it's being heard by the mental health professionals. We want to make sure that they understand your experience and we want to make sure that you're being heard. And so when we ask you to participate, obviously we thank you for doing that, but please, please take the time and participate in these studies because that's the only way we can change things is by making sure that your voice is part of the process and is being heard.

(01:17:36)
So thank you. Well, I'm going to share just a few announcements here if I may. The IPPF is very excited to share that last year in June, the US Food and Drug Administration or FDA approved Dupixent, also known as dupilumab as the first biologic treatment for adults with bolus pemphigoid. And this is a significant milestone for our community and it offers new treatment options for patients with bolus pempigoid. And to learn more about Dupixent and its approval, you can read more about it on the IPPF website by scanning the QR code on the screen and make sure that you read about the Dupixent MyWay section on the page when you get to the website as it highlights a patient support program that can help enable access to Dupixent and it does offer financial assistance to eligible patients also one-on-one nursing support and a lot more.

(01:18:35)
So please scan the QR code and visit our website for that.

(01:18:44)
A diagnosis for pemphigus and pemphigoid can leave people feeling very scared, as we just discussed, isolated and overwhelmed. Once they find the IPPF, everything does change and you can find answers, support, and community and a community that understands and that support is only possible because all of you. So your gift really helps the IPPF. So it allows us to reach patients at their most vulnerable moments, provides trusted education and peer support, helps us advocate for access to life-changing therapies and treatments and it helps us remind patients that you're not alone. You're not alone in this disease. So with your help, people with pimpigus and pimpicoid don't just survive, they thrive. So take a moment and donate today. You can scan the QR code on the screen and just remember that together we are changing what is possible.

(01:19:45)
We are excited to share that the IPPF has added six new research questionnaires. Marnie

alluded to this earlier, so I'm not going to spend too much time on this slide and we've talked about how important your voice and research is. Scan the QR code on the screen, take time to join the IPPF natural history study. The more information that we have for researchers, the sooner we can find cures for our disease and the sooner we can improve diagnostic delays and really help everybody that is suffering from pemphigus and pimphoid. One other note about the IPPF natural history study is that it is now easier than ever to use. There's now actually a mobile app that's available to you, I am rare app and it is free to download. You can just go to the Apple store or the Google Play Store. It's called type in I am rare and it will pop up and you can actually do your surveys right from your mobile phone, which is great.

(01:20:45)
So that'll save you some time. I am excited to share that registration for the 2026 IPPF Patient Education Conference is now open. So you can now go and register for this year's conference. The conference will be hosted from August 28th through the 30th in Chicago at the Voco Downtown Riverwalk Hotel. And this is more than just a conference. If you've never been to one of these, it's actually a powerful weekend of learning, connection and community. So whether you're newly diagnosed or you've been living with pemphigus and pemphigoid for years, this event is really for you.

(01:21:26)
It can be truly life-changing. You'll hear directly from world-renowned experts, get practical tips that you can use right away. And most importantly, you get to connect with other people who truly understand what you're going through. Early registration does end June 15th, so don't forget to register. So right now you get a discounted price for being an early bird, so I would recommend registering right away and we can't wait to see all of you in Chicago this year. You can stay in the know about what's going on in our community by signing up for our email list and you'll get exclusive updates on this year's conference, learn about upcoming webinars and events, and also get the latest news on Pemphigus and Pemphagoid and our community. Joining is easy. You just scan the code on the screen, click the menu bars on the upper right-hand corner and click join our email list and then enter your info and then in the pop-up box and that will help you sign up and stay informed.

(01:22:35)
So join the email list.

(01:22:39)
Have you had a chance to explore the IPPF’s Patient Resource page? If not, now’s the perfect time! Whether you’ve just been diagnosed or are seeking trusted guidance on managing and treating pemphigus and pemphigoid, our Guide to Pemphigus and Pemphigoid is an essential resource. It’s filled with medically reviewed answers, practical tips, and expert insights to help you navigate your journey with confidence. We’ve made the guide available in multiple languages, so it’s accessible to as many people as possible. In addition to the guide, our Patient Resource page offers a wide range of educational materials to support you.

We hope these resources empower you with the knowledge you need to live more comfortably with pemphigus and pemphigoid. Visit the Patient Resource page today and explore all the information we offer.

(01:23:40)
If you are looking for a doctor who understands pemphigus and pemphigoid, be sure to check out the IPPF Find a Doctor Directory. This tool allows you to search for doctors in your area - or anywhere in the world - who are experienced with these rare diseases.Scan the QR code on the screen or visit our website to get started!

The IPPF has several upcoming support group meetings. If you'd like to join a meeting, visit our Support Group page to find an event and to register. We are also looking to expand our support network so if you're interested in starting a support group in your area, please contact Becky Strong, at becy@pemphigus.org. It's easier than you think and a great way to give back and help others find the support they need.

(01:24:41)
Join us for our next Educational Webinar on Thursday, April 16th for an exciting presentation on “CAR T in Pemphigus Vulgaris: An Update on the RESET-PV Clinical Trial” sponsored by Cabaletta Bio. Scan the QR code on your screen or visit our event page to register for the webinar. We hope to see you there.

Thank you again to everyone that joined us today. A recording of today’s presentation, along with a survey, will be sent out after the webinar. Good-bye.

(01:25:49)
Thank you, Dr. White.

(01:25:50):

Thank you. Thanks for having me.

(01:25:52):

Absolutely.

(01:25:53):

Bye

(01:25:54):

Everybody.

(01:25:54):

Bye.