

## **December 16, 2020 Patient Education Webinar- Mental Health and Stress Management**

**Becky:** Welcome everyone, this call is now being recorded. I'd like to thank you for being on the call with us today. And a big thank you to our sponsors, Genentech, Principia Biopharma a Sanofi Company, argenx and Cabaletta Bio for making today's call possible. Today's topic is Mental Health and Stress with Lynne Mitchell, a PV Patient and Registered Social Worker. Before we begin, I just wanted to take a quick poll, and just ask you a brief question here. So, you should see it now. How many of you have felt being alone after being diagnosed with pemphigus or pemphigoid? While you're answering that question, I'm going to go ahead and introduce Lynne, and I'm also going to ask you to grab a piece of paper and a pen, because we're going to do a brief little practice as we begin here.

**Becky:** Lynne Mitchell is a Registered Social Worker in private practice in Toronto, Canada. For the past 32 years, she has focused on adolescent mental health, parenting, couples, family work, and work place mental health. She has a longstanding interest in group work and is a firm believer in the power of groups and has numerous presentations, workshops and publications in this area. More recently her work has included living with chronic illness informed by her personal experience with Pemphigus Vulgaris since 2015. I'm just going to close our poll now. And it looks like there has been about 78% of us who have felt alone after our diagnosis. So, thank you very much for taking the time to answer these questions. So before we begin, I just want to go over a few housekeeping items. So now it is my pleasure to introduce you to Lynne Mitchell to discuss Mental Health and Stress. Thank you! Welcome, Lynne.

**Lynne:** Thank you. It's lovely to be here and I welcome all of you who are on the web with us today at various points in your journey. So, I'm looking forward to sharing the answers to some of your questions with you, and hopefully getting some more questions from you as well.

**Becky:** Great. Did you want to start with your practice that you wanted us to do this today?

**Lynne:** Sure. So, what I was hoping for is that, in order to make it really personal and meaningful, hopefully, for you session, to start to think about a goal that you would want for yourself, that's in your control, that's small, achievable and easy to do for yourself over the holidays. Because I know the holidays either we're in them now or they are fast approaching and having a goal for them is a good way to take control of the situation and to try and deal with our stress levels, through having a goal that we can achieve. So think about a small goal. Now, I'm saying small, because it doesn't have to be a huge undertaking on your part. Something personal for you that is in your control. That's the operative descriptor there and that is achievable and small. Write it down either on a piece of paper, or on your device, wherever

you'd like to have it. Keep it in mind as we go through the strategies for dealing with stress over the holidays. And hopefully, maybe you can start to make connections between some of the strategies that we're talking about and how you might achieve your goal.

**Becky:** Great. Thank you Lynne. I've written down my goal here.

**Lynne:** Becky, I meant to say I don't know how our time is going to go. It may not be realistic to share some of them at the end of this session, but we can. That doesn't matter because it's your personal goal anyway.

**Becky:** Great, thank you. So let's start with our first question that was submitted prior to the call. It is, how should I conceptualize good mental health and what am I actually aiming for?

**Lynne:** So it's a good way to start. What is it that we really want to achieve? I'm going to call on the World Health Organization, the WHO. And I know that it's been a very busy organization and it's had its problems recently with COVID but it does have a very good definition of mental health that we can work with. And what it is, it describes mental health as a state of well-being in which we can handle the stresses of everyday life. We can reach our own potential. We can contribute to our society, and we can work in a satisfactory manner so we can contribute to our work as well. So, that is the definition of mental health, that I would like to put forward for us. And it affects how we think, how we feel, and how we act. So you can start to see how COVID and having a chronic illness, such as pemphigus or pemphigoid can have an impact on mental health.

**Becky:** Great. Barbara says that her husband was diagnosed with ocular pemphigoid in August and had to retire early. Because of this, she has had to return to work to supplement their income. She said that their lives have changed completely and now she's not only worried about her husband's health, but their finances as well. Now she's having health problems and feels like the world is crashing down on them. Do you have any advice for people when they feel like things are never going to get better? Or they feel like they can't handle it anymore?

**Lynne:** So Barbara, first of all, thank you for reaching out to us. That is the first step in a long process of how to handle the situation that you're going through. One of the best things that we can do in a situation like that is acknowledge that life has changed for us and not be hard on ourselves around not being able to fix it or deal with it right away. It sounds like being overwhelmed is a perfectly natural way to feel when you're confronted with the situation that you're in. But what I would like to do with you today, with all of you, is look at why do we feel overwhelmed? What's going on for us. When we have a chronic illness such as pemphigus and when we're faced with something such as a pandemic as we are as well. What goes on

physiologically for us because that will inform how we deal with it and also take some of the pressure off us in terms of having to deal with it in a way that maybe doesn't make any sense for us. So when we feel overwhelmed, there are two parts of the brain: one is the limbic system, which that part is sort of the more primitive or rudimentary part of the brain which deals with our emotions. And that part of our brain goes into overdrive. And what happens is it produces cortisol and it makes us feel overwhelmed literally. We've got cortisol coursing through our bodies. The stressors that we feel produce feelings such as anger, feeling overwhelmed, and what we call the fight or flight syndrome. And how do we deal with that? Well, the other part of our brain, which is the prefrontal cortex, I'd like to go like this, because I'm assuming that because it's called pre-frontal, it's more to the front of our brain. We need to appeal to that part of our brain, which is the more rational part of our brain. It has the ability to control and to dampen down the limbic system. How do we do that? The evidence shows that things like exercise, meditation, yoga, mindfulness, healthy diets, good sleep, hygiene, and structure. Having a daily routine and routines that satisfy us. Laughter, things like gratitude journals where we record all the things in our life that we are grateful for. These kinds of activities can actually dampen down the limbic system and try and deal with getting rid of cortisol in our body. So there's actually evidence based strategies for how to deal with those feelings of being overwhelmed that you are so understandably feeling at the moment. So to the extent that we can engage those activities in a way that works for us, we can deal with the levels of cortisol which are coursing through our body. And Barbara, there's a quote by Samuel Beckett, who is an Irish novelist that I want to share with you because I think of it often. It's, "You you must go on, I can't go on. I will go on." So, it's very simple. Sometimes, I just leave out the first part of it and say, "I can't go on. I will go on." The, "I can't go on", is recognizing how you feel. You have to recognize how you feel and acknowledge it, and stay with it, and understand that you have a right to feel that way. And then we start with the, "I will go on", part of it, which tries to re-engage the prefrontal cortex and dampened down the limbic system. That's a long answer to say, it's understandable you're feeling the way you're feeling. And I just wanted to sort of put it in a nutshell for you. There's physical things that you can do, such as the exercise, et cetera, and then psychological things that you can do. Some of which I talked about, which are reaching out to other people, which you did with us today. Gratitude journals, those kinds of things. So that's sort of in a nutshell.

**Becky:** Great Lynne. That's a lot of really great information. Thank you. Our next question comes from George, who wants to know, what's the difference between sadness and depression?

**Lynne:** So sadnesses is a human emotion that is often based or reliant on situations. We get sad over certain situations which are understandable in life. But those feelings of sadness usually come and go. Depression is, by definition, and this is through a psychiatric definition, it lasts for two weeks or more and is usually followed with changes in behavior and feelings such as, feelings of hopelessness, helplessness, guilt. Remember, these are things that have to go on for two weeks or more. Insomnia, or changes in sleep pattern generally, either insomnia or

sleeping too much. Changes in eating habits, either stopping eating or eating too much, binge eating. And then feelings of hopelessness, guilt, et cetera. Those kinds of things. And also losing interest in the things that used to bring us joy, and that we used to enjoy whether it's, well now we would have to say zooming with our family because most of us are not connecting with them in person. But even that is no longer of interest to you, those kinds of things. So it's a very pronounced change in the way that you think and feel. And it has to last for longer than two weeks.

**Becky:** Great. Thank you. And that kind of leads into our next question. Our next question is, how do I know when the right time is to talk to a therapist? Should I wait until I feel like I'm in a bad spot? Or do you think it's important for people to talk to a therapist, even if they're feeling anxious or overwhelmed?

**Lynne:** So when to talk to a therapist? It varies, for sure. Some people are ready to talk the moment they feel sad. And some people just feel that they should be able to cope no matter what. So let me say this about that, if you are having issues, like if you are having some issues in coping, but sometimes it works for you, sometimes life is okay. That is often a good time to see a therapist. And the reason I say that is because the therapist can help you figure out what is working for you on the days when it is working. So that on the days, when it isn't, you can do more of what works for you on the better days. So that while you're still feeling like you do have some good days, you can figure out the strategies, the coping strategies that are working for you. And of course, a therapist can help you figure out your thoughts and feelings, and help you develop some strategies around your thoughts and feelings that might work better for you, generally.

**Becky:** Great. Thank you. And when we're talking about therapists, what's the difference between a psychologist, a therapist, psychiatrist, and a social worker? How do we know who's the right practitioner for us?

**Lynne:** Well, let me start with a psychiatrist. A psychiatrist is a medical doctor, who has a specialized training in psychiatry, and usually is board certified. They are the ones who prescribe medications. In Canada, they are, and I believe in the States as well, they're the only ones which are allowed to prescribe medications for various mental health issues. So that's a psychiatrist, and they may or may not be involved in ongoing therapy. It depends. Sometimes they just consult and deal with medication. It varies from psychiatrist, to psychiatrist, from province, to province, from state to state. A psychologist is a Ph.D. level, person who has studied psychology, is registered with the Association of Psychologists and can diagnose, but not prescribe medications. A therapist can be a social worker like myself, it can be a psychotherapist. I'm trying to think of other designations. A counselor comes to mind and generally their Master's level practitioners. And in Canada, for example, they're all regulated by regulatory bodies and registered with a professional college which regulates their practice. So

often, it's just a difference in education and the kinds of activities that they are generally allowed to do.

**Becky:** Great. Thank you. How do I know if a psychologist or a therapist is right for me, especially if we're not able to see each other in person during the pandemic right now?

**Lynne:** That's a really good question because we know that it's the human connection. It's the connection with your therapist that is the most important. And there's a lot of thinking that it's the relationship which is the most helpful as opposed to the kind of therapy they do or the kind of designation they are, whether they are psychiatrists, psychologists, social workers, counselor, etcetera, or a registered nurse, a psychiatric nurse. So that relationship is important. Most therapists will generally give you a 15 minute free consultation over the phone. And I say over the phone, because email is really hard because the therapist isn't going to be there when you answer the email. And you know how emails can be misconstrued and miscommunicated. So I always suggest an actual phone conversation. Hopefully, the therapist would be agreeable to them.

**Becky:** Great, thank you. Our next question, Maryane wants to know: Are there different types of therapy?

**Lynne:** Yes, there are. First of all, there's different formats. You can see a therapist individually or as part of a couple. You can see them as part of a family, and you can also do group counseling. And within those different formats, there are different approaches to therapy. The most evidence based approach is cognitive behavioral therapy, in which a therapist will help you look at your thoughts and feelings, and how they're working for you. And whether reframing a thought and feeling would work better for you in dealing with a certain situation. There's emotionally focused therapy, which is evidence based for couples counseling. There's systems approaches for family work. But generally, if you've had a conversation with your therapist, my understanding and certainly the way I work is that, most therapists are eclectic, and they will modify and incorporate various different therapies to work for you in terms of what your particular needs are. So they're more eclectic.

**Becky:** Great. Thank you, That's good to know. The next question comes from Tim, and he says, as a patient, is there any advice you can give me and others about how you've coped with things and what you have done to make sure your friends and family know about your diagnosis? Do you have any advice on what you have done to keep your family members in the loop about how you felt throughout your journey with pemphigus?

**Lynne:** Right, and of course, they're a huge player, and how we feel, and in our support. And, of course, it depends, too, on how much you want them to know and for what reasons. And

that's always important too. And it depends where on your journey you are. For me personally, at this particular point, I'm sort of in remission, although, anyways, I won't get into that, but I'm sort of in remission. But one of the leftovers is that I can't eat cinnamon anymore and I have communicated to my family not to put cinnamon in anything they make for me. And I would like them to remember that, but that seems to be within the family and an ongoing joke. But more to the point, what I found useful was that my family was very useful while I was in treatment with prednisone. And I'm sure most of you can relate to that. We weren't prepared for that prednisone ride. Nobody prepares you for that ride. Your family will see you go through it, and they will see what was once perhaps a normal family member, get a little wacko. I mean, I was pretty whacko, but I didn't know it. So what I did was I kept a journal in terms of what worked for me. In answer to your question, I kept a daily journal when I was on prednisone. It wasn't a big long thing about how I was feeling but I kept track of my dosage, when I took it, and how I felt. So that if a family member said to me, Mom, you're more irritable than normal. I would say, I just went up on my prednisone, maybe that's why and if it keeps on maybe I should look at reducing it. So it's really helpful to be in contact with your family so that they can make those observations for you and help you in your journey, especially through treatment. And maybe keep the cinnamon out of their recipes.

**Becky:** Great, thank you, and that question kind of leads into the next one. I know you just talked about journaling but Michael wants to know, what are some ways I can track my mental health?

**Lynne:** On the pemphigus journey, with regard to your mental health, it depends where you are in that journey because there's pre diagnosis, which we know is a very, very stressful time. There is diagnosis, which is no picnic either, right? The, "I have what? Really?" It's like, all through that journey, you've got feelings and emotions. Then there's the treatment. Then there's hopefully remission and then there's flare up. So, I would say, to try and track how you're thinking and feeling on that journey through a journal. It really helped me. Then, you've got a document, which most of us feel like burning on a good day, right? Or certainly after you've been in remission for a few years. But at least you know, because you will forget. We are programmed to forget these kinds of things, how you felt on that journey. So, to be able to journal and track in terms of treatment and where on the journey you are.

**Becky:** Great, thank you. Our next question comes from Daniel and he says that I've heard that stress can make autoimmune diseases like pemphigus and pemphigoid worse. Are their physical symptoms of stress? And, if so, what are they?

**Lynne:** So we know that chronic illness, such as pemphigus or pemphigoid can impact the immune system. As I discussed with Barbara, how does that impact our immune system? Well our limbic system goes into overdrive. It has an impact on our emotional well-being. The cortisol

starts coursing through our body. Some of the symptoms are the cortisol, makes your heart race and whether it's through prednisone or through feeling overwhelmed because of pemphigus you can have insomnia. You can have stomach upset. You can have heartburn. Most of us remember, well, I certainly remember the midnight chugging of pepto bismol in the hope that maybe I'd be able to sleep after seven sleeping pills, but sometimes not. You The energizer bunny just sort of kept going. You can have a panic attack, which can mimic a heart attack. So you have to know and sometimes you won't know, until you present at hospital, whether you're having a panic attack or a heart attack. You sort of have to check it out. So, there are definite symptoms that I've mentioned, about what they are like. But I can't comment on whether stress will cause a flare up in pemphigus. We know there's a correlation, but I couldn't comment on whether there's that impact. That's for a medical doctor to determine.

**Becky:** Thank you. The next question asks, what can I do to help relieve stress on my daily life or stress from having this disease? So, let's try and develop a winter toolbox for how we're going to deal with the stress that we're going to be experiencing in our daily lives, going forward over the holidays as we deal with the pandemic and our pemphigus. So we want to dampen down our limbic system. So we want to do whatever works for us in order to do that. The evidence based activities that go for that are movement, we know that exercise helps us in that process. Structure. The less decision making that we have to deal with on a daily basis, the more structure and routine we have in our lives. When most of our structures have been taken away from us because of the pandemic, such as going to school for some of us, going to work, meeting with our families on a regular basis. We have to create our own structures. That's really, really important. And stress comes with the fear of the unknown. It's as simple as that. So if you develop a routine that works for you, sometimes, hopefully, that stress can be reduced. So, as we said, physical exercise, movement, diet, yoga, meditation. Connect with the IPPF and with the Peer Health Coaches here if you're feeling stressed. They are a wonderful resource. And I speak from personal experience in that. They are a wonderful resource when you feel overwhelmed with your pemphigus and can't cope. So, what does that mean? Connect with others. Reach out to other people. Don't be on your journey by yourself. If you find it difficult, find a way to make it easier for yourself. And with pemphigus because it is such a rare disease, the IPPF is a wonderful resource and the Peer Coaches are a wonderful resource for that. And maintaining a sense of community. Some of the things that we talked about were gratitude journals and laughter. Finding ways to laugh in any way that you can, we know that it works. Diet, we know that Mediterranean helps to reduce stress levels and cortisol levels. You can Google the Mediterranean diet. It's not that complicated, but you'll get a better sense of what it is exactly than I can give you. I'm not a dietitian. So those kinds of things. I hope you can put that in your toolbox for the winter. When I say movement, I'm speaking from a perspective that, I stood up off my chair so I could speak to you, and I'm swaying back and forth a little bit. I find it easier just to move, rather than to sit. If I can walk and talk on the phone, I find I'm less stressed. It doesn't have to be at the gym, it doesn't have to be lifting weights. Find a way that works for you to move. And I remember when I was nauseous from the medication and I just didn't know how I'd go on again, I'd stand up and move. Just breaking that spell, just changing the perspective helped with the nausea. Then the next time I got nauseous,

knowing that all I had to do was get up and move, would help. It becomes a gratifying cycle. So those are all some of the ways that we can deal with stress. I hope that in your toolbox, you'll start to fill up personal ways. Now, I'm giving you information, and I wish I could speak with all of you individually, but you have to make it personal for yourself. What's going to work for you? I'm going to be honest with you, meditation does not work for me but yoga does. I am an ardent yogaist. With meditation I can't control my mind but I know why yoga works for me because I do it with my friends online now. So it's the power of the group. It's the power of doing it with somebody. Knowing that at 10 o'clock on Tuesday, I'm going to do yoga. It's the structure. It's the connection and there I am. So that's what I mean by the toolbox. Find what works for you.

**Becky:** Lots of really great information there. Thank you so much Lynne. The next question kind of ties into stress and says, how can I identify destructive types of stress in my life and what can I do to make sure that I'm avoiding all the unnecessary stressors?

**Lynne:** On top of everything now we have pandemic stress. What I want to say about how we handle this stress going forward is, in Canada here and in Ontario here, I know you have similar bodies in the United States, to listen to your public health officials. And follow the advice they give you about what to do and what not to do. Because, I'm suggesting that we all, as pemphigus and pemphigoid patients, reduce our risk in these pandemic times. So, just follow public health guidelines and, why do I say that? Because then you don't have the stress of deciding for yourself what to do because you don't know. So at least you're following the best advice of the people who do. So follow the public health guidelines about what's safe for you to do in your area. Reduce your risk, and that will help reduce your stress.

**Becky:** Great advice, Lynn! Thank you so much. Our next question goes back to when you were talking about movement. Is it proven that exercise can help reduce stress?

**Lynne:** Yes. The endorphins that are released when we move help reduce the cortisol levels in our body. And doctors will often prescribe exercise as an adjunct therapy for depression and anxiety. Because it's a non pharmacological way to reduce the cortisol levels in your body and get your neurotransmitters to fire in a more efficient manner. So, yes. And, as I said, it doesn't have to be an hour workout at a gym or in your basement with weights, etcetera. The only exercise that I will self motivate myself to do almost daily is walking. Everything else I have to plan and structure for. So that's what I mean, know yourself. Don't fool yourself but don't be hard on yourself. Just because you don't want to go to the basement or go online. Like I can have the best intentions at four o'clock, I'm gonna go find a YouTube exercise for yoga but when four o'clock comes, there's always something better to do, right? But if you know that you've got a structure set up with people to perhaps to do it with, maybe that will work better for you. So, find what's going to work for you and keep moving. And as I said, I can put on 5000 steps talking to my sister in Winnipeg, just walking around the house, talking. That counts as movement too.

**Becky:** My tip with that is I start my day with exercise. I get up a little bit earlier, and I do it, because, one, no matter what happens today, I've done something for myself. And two exactly what you said Lynne, there is always something better or the day is going to beat me up, and by the end, I'm too tired. So I just start my day and it just makes me feel better. And it's that rush of endorphin in the morning that makes you feel a little bit better about everything. So that's my tip. It could be the stuff heart attacks are made of, I don't know, but that's just what works for me. Thought I would share.

**Lynne:** And also, it's the structure of knowing that, Becky, right? And that's the other thing. You don't have to start thinking about when you're going to do it if you have a prescribed time. And it doesn't have to be a major commitment of time.

**Becky:** Right, absolutely. Our next question is a really great question, I think. How can I maintain social connections especially feeling lonely with COVID-19 and having a rare autoimmune disease? What if I feel lonely?

**Lynne:** That's the real question because we're human beings and we're programmed for connection and for community and for relationships. And, I think that it's true, it's been one of the biggest challenges of this whole business. Whatever way that you can, to reach out to whoever you can, through whatever medium you can. I keep referring to the IPPF, the Peer Coaches because they are a wonderful resource. Once you do one thing, in terms of trying to feel and it's pretty non threatening to reach out to them. They're not going to reject you. A friend might, a family member might, if we have those feelings around our isolation and loneliness about rejection. The IPPF peer coaches are not gonna reject you. Guaranteed. I speak from personal experience. So, it's a safe place. So, if you're feeling lonely, look for safe places to connect. One of them is the IPPF, and whatever else feels safe in your life to connect with and try and put some structure around it too.

**Becky:** Great, thank you. Christy asks our next question and wants to know how can I reframe a situation and find a more balanced perspective?

**Lynne:** That's a great question because implied in that question is, stuff happens in life, now what do I do? So we've got COVID and we've got pemphigus, can't change those. There are people in the world who are trying, we may even be trying, but all that's left for us to do is how we're going to cope with it. The only thing we can control is our responses. So find a thought that works for you. Any way that you can find to say, "I got this, I can do this. I'm just going to do something small to try and control the stress I'm feeling around the pandemic today. I'm going to get my groceries delivered. I don't want to go out. It's okay, I'm gonna get my groceries delivered." And to be okay with it, to give yourself the permission. It's not coping out. That's the

reframe, right? It's whatever's going to work for you. To take the situation and to say, I can't change what is. The only thing I can change is how I respond to it.

**Becky:** Great, great advice, Lynne. Thank you. Our next question comes from Andrea and she wants to know, how can I tell if I'm feeling depressed or if it's just the prednisone.

**Lynne:** Yeah, well, we'd have to do a regression analysis on that one. But as I said before, the only thing that worked for me, and you will find your own way through this, but, was to keep a journal so that I knew what my dosage was and how I was feeling. And often, there was a direct connection. Then, to be able to discuss it with your family members, in terms of what they're noticing and to discuss it with your physician as well based on your journal and what you're seeing. Maybe there's some modification that can be made in your prednisone. Maybe you can go up slower, or you can reduce five milligrams? Both of which happened for me, and I felt better as a result. So, it's really important to be able to track your feelings in order to know what's the prednisone and what's actually depression. And the two get so bound up in your treatment, they really do.

**Becky:** Great advice. Thank you so much. Our next question comes from Amy Lynn, and she wants to know, do you have any apps or websites that you recommend to try and track my mental health or where I can learn or get more support?

**Lynne:** Yes, so there are so many of them. Maybe I can simply send them to you, Becky, and you can post them.

**Becky:** Yeah. That would be helpful.

**Lynne:** Yeah. The CAMH Foundation, it's the major psychiatric hospital in Toronto. It's sort of a hub in Ontario here. They have a wonderful website which anybody can go on to. It's coping with stress during the COVID-19 pandemic. Of course, the IPPF website is wonderful. Headspace is good. The Calm app, I've listened to their bedtime stories sometimes, I do confess. Another app called Smiling Minds. Some other apps are: BetterHelp, Youper, Companion, Clarity and Woebot.

**Becky:** Great Lynne.

**Lynne:** Yeah, I don't know about Facebook and YouTube. I tend to go to the apps and the sites that I know have been vetted because you can get some pretty far out stuff.

**Becky:** Yeah, Absolutely. So, if you wouldn't mind sending me those afterward, and we'll see about getting those posted on the website. Those will be very helpful to know about.

**Lynne:** Okay and some of them will help and people can do some online checking in with you in terms of your mental health. If you lived in Ontario, we have three sites where they do actual CBT therapy with you online.

**Becky:** Oh, wow.

**Lynne:** Yeah, but I think you have to be a resident in Ontario.

**Becky:** This is just a question that hasn't been submitted, but I just have a question. If you're looking for a mental health professional, are there any reliable sites that will help me find resources and professionals in my area?

**Lynne:** Yes. Most of my colleagues here, in Ontario and Toronto, are listed on the "Psychology Today", Find a Therapist site. I know all the states have their own division. Wherever you are, in North America, I think you can find a fairly reputable therapist on "Psychology Today". It's a magazine, I would try "Psychology Today".

**Becky:** Great, Kevin is asking, Is it good to use a distraction to manage difficult thoughts or feelings?

**Lynne:** And my answer of course would be yes, as long as they're positive distractions and they're not things like, excessive drinking, gambling, overusing drugs or alcohol or prescription medications, internet addictions or shopping. Any of those kinds of distractions I would put in the not so wonderful category. But positive distractions, anything that you find makes you feel better. Now, the addictive distractions will also make you feel better but not in the long run. It's a fine line. I think you know what I'm talking about. Watching Netflix is just gonna give you a headache. For eight hours at a time, it'll give you a headache but it won't deplete your bank account or your liver.

**Becky:** Great, thank you for that. So Julia is asking, as a caregiver are there any signs we should look for while caring for a loved one to make sure that they're mentally doing okay?

**Lynne:** Yeah, that's a really good question. Look for negative changes, some of the depressive attributes, some of the things that you might feel when you're depressed. If your loved one

doesn't want to get out of bed or doesn't want to shower, doesn't want to get dressed. And this is consistently for a two week period. They don't want to eat, or are eating too much. They are telling you that they don't want to go on, that they're feeling hopeless or guilty. Or they have thoughts of self loathing. Not sleeping or sleeping too much, any of those. But go on for two weeks or more. Those are signs to track and to follow up on with your loved one if they go on for any longer than two weeks.

**Becky:** Great, thank you. Our next question comes from Brent, and says that I recently read an article about self care for caregivers, and they discussed one of the ways for caregivers to look after themselves is to redefine success. I also feel like this is important for patients as well, since sometimes treatment plans don't exactly go according to plan, and sometimes we have flare ups. What ways do you feel that us patients can redefine success, or deal with some setbacks that we have in our own lives with our health?

**Lynne:** That's a really good question. I think the recognition that things rarely go in a straight line. Sometimes the best thing you can hope for for a person who's in treatment is that there will be no glitches, but we know that there will be. So how do we deal with that? How to reframe that? To define success one step at a time, to not go any further down the road than the day that you're in. To take a very, very, short term approach to success. How was today? How is this morning? How is this hour? How was breakfast? Define it in, so far so good. Okay, let's see how the next part goes. So to define it in small, easily, measurable, short steps and to not go any further down the road than you have to.

**Becky:** Great, thank you. Next question comes from Ross. And we've kind of touched on this already, but I think the second part of the question is important. He wants to know, are there certain behaviors that we can monitor in our friends and family to be on the lookout for depression? If we feel our family or friends are depressed, what can we do? Is it better just to listen or to offer suggestions to make things better?

**Lynne:** So when I was training to be a therapist, for the first six months, I was only allowed to repeat whatever my client was saying. No questions. No assessments, no judgements, no criticisms. The best gift you can give to somebody who you think might be depressed is to just actually listen to them, and let them know that you've heard them without judging them, without criticizing and and without offering any suggestions as to what they should do. Even if it comes from the best place in your heart, and the best intention. Even if you think you know what might work for them. The best thing you can do is just listen and acknowledge that you understand how they're feeling. That's the only thing that I can suggest at this point for listening to somebody who you think might be depressed.

**Becky:** Thank you Lynne. Really great advice there. Our next question is, sometimes it's hard to get someone to open up to talk about how they're feeling or what's going on with them emotionally. What are some ways that you can show a loved one that you're there for them, and maybe help them gain some trust so that they might open up to you eventually?

**Lynne:** Following along from the last question, just show up for them. No judgements, no criticisms, just listen. And I know that many of us are fixers, right? We think we know and we want to help. It comes from such a good place, but it's often not what people need to hear. So, what I always suggest is take that intention, and try to modify it to what the person actually needs in that moment, which is just to be listened to, just to be heard and acknowledged in the way that they're feeling. And as to whether or not they actually open up to you. I mean, I think that we don't have to fix all the problems that we know might be bothering this person. Just to acknowledge that we hear the problems, and maybe we could help them problem solve around how they want to solve the problems in terms of going to a therapist or whatever it is they might do. But actually just to be able to listen to them and to start where they are, without offering to help, or to solve any problems, even though it comes from a good place.

**Becky:** Great, thank you. Our last question for today asks, with COVID-19 and so many people social distancing and isolating I think many people are not only missing human interaction, but also human touch. Do you have any suggestions or strategies for those who are missing human touch such as having a hug?

**Lynne:** That's really tough. That's the one that brings out all the emotions that we are feeling at this time with COVID and social isolation, and facing the holidays in a winter without connection and hugs. We know that's coming. So I think what you're asking is how do we prepare for that? And that's a really tough question. I mean, certainly to maintain the virtual connections but also any of the strategies that are in the toolkit that we talked about today that will release endorphins for you. Laughter, exercise, movement, yoga. Reading a good book, journaling, gratitude. Any of those things that we talked about hopefully will help us release the feel good endorphins that a hug gives us. It can't replace a hug, for sure. But maybe soon we'll get to the point where we can do that my family calls them back hugs, you hug back to back. But not now. We did that, maybe once or twice in the summer, but I wouldn't do that now. Now, we have to keep it virtual, and we have to show our love in other ways and feel the love that comes back in other ways. And we have to hope. And that's where hope comes in. That's where the reframe comes in. We're forgoing the hug in the hope that we can get many more when it's safe to do so and when we won't make each other sick.

**Becky:** Thank you, Lynne. There is one other question that has come in. The question asks, what to do and how to handle the stress of knowing that we have elderly family members, but at the same time we don't want to be around them to get them sick? But also with the knowledge that maybe next year they're just so elderly that they're not going to be here. How to

handle that kind of stress of knowing what to do with your family and knowing that you're making the best decision that you can?

**Lynne:** I think you're talking about having no regrets and that's a tough one. What I would say is I would talk to your family. I would talk to your doctor, I would talk to your loved one's doctor and see what you can come up with in terms of a family strategy around connecting with the person so that you have buy-in from all of the major players around how to do this. So that you don't take it upon yourself to just do X, Y, or Zed even with the best intentions. But you speak to your doctor. You speak to your loved one's physician and you speak to your family, and you come up with a plan that you can all live with, regardless of what happens.

**Becky:** Great. Great advice. Thank you so much. You have given us a lot of information and have definitely filled up our toolbox to be able to give some really solid foundations of how to better take care of ourselves this winter with our mental health. And I think our mental health is every bit as important as our physical health and a lot of times could be overlooked. So thank you for being on the call with us today. And I also want to give a huge thank you to everyone who joined us today, or who will be listening to this recording. And, of course, thank you to Genentech, Principia Biopharma a Sanofi Company, argenx and Cabaletta Bio for helping to make today's call possible. Before we go, I have a few announcements:

Our goal at the IPPF is to create a brighter future for all those affected by pemphigus and pemphigoid. As a community, we've made great strides in recent years, but there's still much work to be done. Your support is critical to fund the future for pemphigus and pemphigoid patients. Help the IPPF reach their goal of raising \$40,000 by the end of the year by making a donation online. Thanks to a generous gift from the Unger Family Foundation, all new or increased Healing Hero donations will be matched through the end of the year. Your donations will ensure that our patient support programs are available to all those who need them today, tomorrow and for years to come.

Also, if you are interested in continuing to help support the IPPF you can become a healing hero. Healing Heroes fund the future of the IPPF community by making sustaining, monthly gifts to support our mission of improving the quality of life for all those affected by pemphigus and pemphigoid. No amount is too small, even a \$5 or \$10 monthly donation goes a long way and continues to allow us to provide for the greater good of our community.

If you have not registered for the IPPF's natural history study we encourage you to do so. The IPPF Natural History study is a patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US Food and Drug Administration (FDA). You can register today at [www.pemphigus.iamrare.org](http://www.pemphigus.iamrare.org). This online data system collects, stores, and retrieves patient data for analysis in research studies. The more data we can collect, the better the information we can give to researchers, the sooner they can find better treatments, earlier diagnosis, and one day – A CURE!

Our next Patient Education Webinar will be in January to discuss how you can get involved and become an advocate during the 2021 Virtual Rare Across America. This event is a great opportunity to have your voice heard, share your story with legislators, and help get legislation passed that affects our rare disease community.

Lastly, If you have a question that didn't get answered on the call, or have additional questions please e-mail Becky Strong, at [becky@pemphigus.org](mailto:becky@pemphigus.org), or call (916) 922-1298 x:105, and we would be more than happy to help.

This call recording will be sent out with the survey following this call.