

## April 2, 2020 Patient Education Call Transcription

**Becky:** Welcome everyone, we are sorry we are starting a bit late we were having some technical difficulties but we appreciate you hanging with us. This call is now being recorded and I would like to thank you for being on the call this evening. Our Speaker today is Lynne Mitchell. Thank you for joining us! On the call today we will discuss Mental Health and Wellness while living with Pemphigus and Pemphigoid. First let me introduce you to our speaker this evening: 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 workplace 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. Now, it is my pleasure to introduce Lynne Mitchell to answer your questions about Mental Health and Wellness.

**Becky:** So Lynne, just to start off do you want to share a little bit about your story and how you became involved with the IPPF?

**Lynne:** Yes I'd be happy to, Becky. And I am very happy to be on the call with all of you today wherever you are, sheltering in place, hopefully healthfully and safely. I am a registered social worker in Toronto, Ontario Canada. My comments today and answers will be not at all prescriptive or diagnostic but rather based on my experiences as a mental health professional but also very much informed by my experience as a pemphigus vulgaris patient since 2015. And like most of you I had a journey that brought me here to this web call today and the IPPF. So in the scheme of things it took me a very short time to get diagnosed, only 6 weeks which I understand is really quite a short period of time for many of us who have been on that journey and then until I was actually on treatment. And while I was on that journey I was as lost as all of you. But once I got the diagnoses I just assumed that the IPPF existed. I googled and there it was and thank you to all who went before me on their journeys and created this wonderful organization. I had an experience in 2013 where I had a colon resection and I ended up with a colostomy and I found that the people who could help me the most were the people who were living literally in my skin and so I used their services quite a bit. So when I was diagnosed with pemphigus I just really wanted to connect with the IPPF and their wonderful peer health coaches who literally live in our skin. I mean we are all living in the same skin together. So I can't say enough about how their peer health coaches, too many to name at this point, helped

me in my journey. So that's really how I came to be speaking with you today.

**Becky:** Great Lynne, thanks. And you kind of bring up a good point that we as patients are really focused on our physical symptoms and learning to live with pemphigus and pemphigoid but sometimes we forget that in our physical illness about our mental and emotional health. What can we do to monitor our mental health as we would monitor our physical lesions?

**Lynne:** Well such a multifaceted question because really we are on a journey. There are mental health issues at the various stages of the journey. There is pre diagnosis, when you are figuring out what the hell is going on, what is wrong with me and all the emotional issues that arise at that point when you are experiencing physical symptoms but you don't know what they are yet. Then diagnosis, then the treatment, then the remission, then the flare ups. So as you can see there is all along the path of the journey that we are on. But I think that it's particularly important that as we monitor our physical lesions and our treatment, is to monitor I think for me personally what worked was a daily journal of what medications I was taking, the exact doses that I was on whether it was an increase or decrease, how I was feeling and how I was behaving so that at the end of my journey or on my journey rather and at the end, I had a log of how I felt and how it related to the medication I was on. It really is an invaluable resource because as we know, prednisone and I am assuming that many of us have been on prednisone and many other things, can have an impact on the way that we're feeling, thinking and behaving. So to be able to monitor that in very concrete terms in a journal really helps when we try and identify how we are feeling in relation to our lesions in relation to our medications. And my family was only too happy to help me point out how my behavior was impacting them and also if they noticed any change in my behavior. Which when you are in the throws of what you are going through you may not be so amenable to hearing but it is an important marker in terms of behavior change. If you are normally one particular way and all of a sudden you are another way that may be a sign that the treatment of your lesions is having an impact on your thoughts, feelings, and behavior. But really to try and get a handle on what is medication related and our feelings around it.

**Becky:** Great, so as we go through and ask some questions I just want to lay out some definitions quickly. What is the difference between feeling sad, anxious, or depressed? What are the differences in those and how can we tell the difference between all of those?

**Lynne:** Yeah, that is a really good question. Sadness as far as I understand and have experienced from my clients and my own personal journey is a human emotion that we all feel from time to time and it can be very much events related. Related to loss, changes, the whole

gamut of events that might occur in our lives. And the effects, we feel down and we experience feelings of sadness, we are not as happy as we used to be, etcetera. Depression by definition, clinical depression is something quite different. It has to be sustained for at least 2 weeks. Sadness can come and go, depression is something that is pretty much sustained for 2 weeks. It's associated with other markers as well such as low energy, poor sleep, poor appetite, no interest in things that gave you pleasure originally, feelings of guilt, hopelessness, worthlessness, and it can induce feelings of suicidal thoughts. So that really is the difference, one being sort of I don't want to call it a garden variety human emotion, I mean who needs it? But we all experience it but depression is something that is different and has to be sustained for at least 2 weeks with many of the markers that I indicated.

**Becky:** Great, thank you. Some questions have come in, and what can be done if we are feeling sad about having our disease or getting a diagnosis of pemphigus or pemphigoid? And a related question, what will be different or what else can I do if I am depressed?

**Lynne:** So when we're feeling sad and depressed, we know that there is a neurotransmitter called serotonin which really helps us control the feelings of well being. So the best thing we can do is try and improve our levels of serotonin through techniques that really are evidence based such as exercise and getting moving. We know that exercise produces the endorphins that make us feel better, it is evidence based. And many doctors will actually prescribe exercise as an anecdote or prescription for sadness and depression. So increasing your serotonin levels by doing things that you enjoy. Mindfulness and yoga are 2 other evidence-based approaches to dealing with sadness that we know improves the way that we feel and calms us down. And in terms of what will be done or what will be done differently if I am depressed? Well depression really requires an assessment by a clinician. It's really something that is hard to determine on our own. You really are best to seek help from a clinician, a mental health professional, a doctor. And some non drug related things they may prescribe which will impact on your serotonin levels include things like CBT therapy which helps you with your distorted thoughts such as "I don't know what this is", "I'm never going to get better", "Life as I know it is over". Those are the kind of thoughts that CBT therapy can help you cope with and develop better strategies for. Exercise may be prescribed, mindfulness, group therapy. We are all in the same boat together. The IPPF website has, I believe, you can correct me if I am wrong Becky, a place to ask questions and you can see all the questions that come up, many of them similar perhaps to the ones that you are feeling. And the feeling of being part of something not just alone with your questions and your sadness on an island that nobody else is on, helps mitigate those feelings of sadness. And again things that you enjoy and of course the support of family, friends, or anybody that you turn to when you need support.

**Becky:** Great Lynne, that is a lot of great information.

**Lynne:** Oh I forgot to mention some of the pharmacological efforts to be done if you are depressed. A physician may discuss prescribed antidepressants with you, which again, we'll work on your serotonin levels.

**Becky:** Great. This question kind of plays right into that. Can my regular doctor help with this or do I need to go to a specialist?

**Lynne:** Well, certainly in Canada for sure, we would start with our family doctor who is very, very well equipped. I mean, feelings of sadness and depression are so widespread. They're very well equipped to determine and to assess and to pick up on them and in their office to help you deal with them and to assess their all kinds of depression scales that they can administer with you. And then you can see whether you fit the diagnosis for sadness, or which is not a diagnosis, or depression. So absolutely, a family doctor could help. And in Canada you need a family doctor's referral to go to a psychiatrist. It's your first stop. And in the U.S. I'm not in the but I think it is also.

**Becky:** Yeah, I think it might be dependent on your insurance provider. So that's a good thing to check with before going to a provider. So this is a very timely question. In what ways is the Coronavirus affecting our mental health and what are some good ways that we as patients with pemphigus and pemphigoid can cope during this global crisis?

**Lynne:** Yeah. Wow. That really is a huge question, but let's tackle it bit by bit. So what do we mean by mental health? It's always good to know exactly what we're talking about. So the World Health Organization (WHO) now they've been pretty busy during this time of pandemic, but I guess in their headier days, they actually defined mental health as a state of mind in which individuals can realize their potential, handle normal stresses, work productively, and contribute to the community. So you can see already that the pandemic has got a role to play in and how it might be affecting our mental health because so many of those things are affected already. Our mental health affects how we think, act and how we feel. So you can see how a pandemic as could the chronic illness of pemphigus and pemphigoid they share some similarities. At the moment, neither can be prevented by vaccines and neither can be cured by medication at this point anyways. Now our chronic illness can be put into remission but can't be cured. So you can see the similarities right there, but both of them impose an unplanned, emotional impact on our life. So let's look at how the brain is set up to handle this, this double

whammy of the COVID-19 and pemphigus. Because it's going to be affecting not just us at this point, but the entire world literally is starting to understand how we feel as sufferers of chronic illnesses. So in that sense, we couldn't be in a bigger boat because we're all having to figure this out together. So how is the brain set up to handle this as I understand it? So there are two competing lobes in the brain. The limbic, which is the primal part of the brain, that ancient part of the brain, which handles our rudimentary emotion. It's the heart of stress, anger, anxiety, and it sets up the flight or fight syndrome. So that's what makes us anxious. It pours cortisol into our body. We're ready to, stay up all night, which many of us do when we're feeling very anxious. So the competing system to that, and we certainly need to harness its power, is the prefrontal cortex, which is the rational sort of executive controller of the brain, which can dampen down the noise of the limbic system. So whether you're dealing with COVID-19 pemphigus or both of them, you need to get that limbic system that's in overdrive damped down. So how do you do that? How do we reduce our cortisol levels? I mean, cause literally that's what we need to do. Well we know the evidence shows that there are evidence based ways to cope, exercise, movement, relaxation techniques, mindfulness, yoga, anything that you enjoy that gets the rational part of the brain back in gear. As I'm speaking to you because I've got cortisol coursing through my body at the moment cause I want very much to meet your needs and answer your questions in a way that is helpful for you, I'm walking. I have found in my worst times of pemphigus, in my worst time during my colon resection that when I was feeling sick to my stomach, nauseous, headachy, whatever, if I simply got up and moved it changed, it broke the spell and I was able to feel back in control. Anything that will help you get back in gear. And unfortunately, alcohol, caffeine, and cannabis just are not what's recommended at this point, at least not to excess. I mean, I guess with everything it's in moderation, but certainly they're not what's going to help you at this point. And we usually reach out to family and our support systems when we need help damping down our anxiety. And of course that is being challenged at the moment in, at least in a physical way. But of course, we're all, as we're doing today with each other reaching out in the best way that we can to maintain our sense of community as fellow chronic illness experiencers. And supporting all your family and social connections, healthcare workers, whatever support systems you tap into to try and continue to do that as we go through this together.

**Becky:** Great. Thank you so much. How much does stress have an impact on having pemphigus or pemphigoid in general, outside of a global pandemic?

**Lynne:** How much does stress affect pemphigus and pemphigoid? You mean in terms of bringing on lesions?

**Becky:** Bringing on our disease or are helping to keep it in remission?

**Lynne:** Yeah, that's a really good question and I think the jury is out on that. To the best of my knowledge the medical sciences believe that stress plays a role, but they're not sure. In the same way that you know, you get shingles can be prompted by stress. But I don't know that they're absolutely sure Becky, but I could be wrong on this. It's not something that I have directly at my fingertips. But in terms of the stress that it brings on that certainly, whether stress brings on the lesions, we still have the stress whether the lesions come or not. So anything that we can do to deal and to reduce the level of stress in our life as we've discussed, try to dampen down your limbic system, get the cortisol to dampen down in your system, anything that relaxes you, anything you enjoy, such as movement or exercise. And then we should also talk about a healthy diet and a stable routine also. Especially in these times when all our routines and structures have really been eliminated for us to try and re-insert some level of structure and routine in our life because that takes away the fear of the unknown. You wake up every day, you feel stressed. What am I going to do today? I used to go to work, now what am I supposed to do? So any kind of routine that you can impose. Get up, brush your teeth, comb your hair, have a shower, have your coffee. For me, it's the coffee. I get out of bed and I live to make coffee and then everything else falls into place for the rest of the day. Whatever routine you can establish because it's the fear of the unknown. The unknown of the hours of the day, which are stressful and stress provoking both for our illness and for the pandemic that we're faced with right now.

**Becky:** Absolutely. And you brought up something else. You talked about having a diet. Are there any foods you mentioned about having a healthy and balanced diet, but are there any happy foods or foods that can help us to feel happier?

**Lynne:** Well, I think we all have our happy foods, but the question is whether they really make us happy or not. Right? I'll leave that for all of you to answer individually, but I think yes, we know evidence-based, the Mediterranean diet is helpful in maintaining a decent level of cortisol in our system. It helps us eliminate stress. And what that is it's based around things like plant based foods, fruits, vegetables, nuts, herbs, some dairy, fish, poultry, eggs, some red meat and whole carbs. What did they call them? I'm not a dietician, but I certainly know the moderate amounts of dairy, poultry and eggs. And I'm just trying to think of the words for the carbohydrates. It's escaping me right now. But I think the people on the call probably know it better than I do. Complex carbohydrates, complex carbohydrates.

**Becky:** Well, great. Well thank you. So there is a couple more questions kind of dealing with

the COVID-19 and this person says that they're not anxious or upset about pemphigus or pemphigoid or even COVID-19, but I have some family members who are what can I do or say to help ease their anxiety about what's going on in the world?

**Lynne:** Wow, that's a really good question because we are all really connected to others and we want to try and meet them where they are. So what I would say is meet them where they are. Acknowledging and it's acknowledging that you understand their anxiety and that you empathize with it. And empathy is really just your ability to understand somebody else's feelings. This is particularly true also for if we have children at home who we are going through this with. Kids get anxious too. So to be able to validate their anxiety, don't talk them out of it because they feel it too. And as do your family members, so just to validate their anxiety, but on the other hand, to take the pressure off you, you don't have to try and make it, you don't have to solve that problem for them. All you have to do is listen and understand and not judge or not criticize. If I could put it in its simplest form, that would be it. And if they really are having trouble, either kids or family members then have an honest discussion about a referral to a mental health professional for an online session if they're having trouble coping. But it really isn't your job to solve the problem for them. You just have to listen. But that's a huge job in itself and a very important one.

**Becky:** And I think that's a really important distinction too Lynne. Are there any mental health apps that you could recommend at this time or any useful resources on YouTube or Facebook or any other social media or through the internet that can help us feel connected and help keep up our mental health during this pretty difficult time and in dealing with our own disease as well?

**Lynne:** Yeah, it's a really good question. And yes, I have a couple of recommendations but I just wanted to say something about Facebook and YouTube, just to be careful. I mean, those are not the vetted sources. They've not been verified. There are people doing all kinds of things and saying all kinds of things. So just be careful. We're inundated with social media, so choose your sites carefully. So some of them that I do know and would recommend in terms of meditation and these are like, you can do five minute guided imagery and meditation sessions on them are Headspace and Calm. In Canada, you can go online and use their website, it's a very good website, it's the CAMH foundation coping with stress during the COVID pandemic. And then you'll get on there coping with stress. There are so many of them maybe I could send them to you Becky and you could post them. There are several apps called Better Help, Happify, Yooper, Companion and these are all that have been vetted by mental health professionals that I trust. Snap Clarity, Woebot. There's a lot going on. And then there's a

website also.

**Becky:** Yeah, Lynne if you wouldn't mind sending those to me via email after the call and then if anybody would like them, we can send them out. Then we'll probably post them on our link as well where we have information for the Coronavirus as well so I think that'll be very helpful for our community. You kind of alluded to this a little bit earlier about how physical movement affects our health and is there like any specific movements that we should be doing?

**Lynne:** Well the research does show that exercise helps produce the serotonin and the endorphins. And these are the feel good hormones, the same neurotransmitters that work on the brain that antidepressants generate. So often a physician before prescribing medication will say look, try a form of exercise. Now it has to be something that you enjoy and that you're going to stick to. Like knowing me personally, there's no point telling me that I have to bench press 50 pounds to feel better because it's not going to work for me. There are things that I enjoy doing, which I can stick with and do. So whatever it is for you. I found that moving also helped me with my physical ailments as well during my bad times of prednisone and CellCept, lesions, et cetera, and nausea. That moving, just getting up and moving, walking outside. I know even now we're compromised with walking outside. If you have a backyard to walk and I have to tell you we spend a lot of time on devices now. I'm not sitting down. I'm pacing up and down in my kitchen. When I talk to my sister on the phone in Winnipeg, I walk up and down in my backyard, I can put on 5,000 steps. So you know, like you don't have to be sitting when you're talking. You don't have to be sitting. You can get up and move. Just those little things in this time of the pandemic and of the crisis, when we do feel kind of restricted in our physical movement, it's a challenge to keep moving so find what works for you. Go up and down the stairs if you have them a hundred times. I keep telling my husband I'm doing him a favor sending it down to the basement 40 times a day.

**Becky:** I think you bring up an interesting point. We don't need to put gym clothes on and go to a physical gym. There's ways to get little bits of movement throughout our whole day that really can add up at the end of the day. And I think that's a really great point and a good thing to remember.

**Lynne:** Walk and talk.

**Becky:** Absolutely. So kind of along those same lines, and I know you were talking about getting up and talking and it's really funny that you say that, cause I usually stand during these calls as well. But are there any stress relieving techniques that I can do while sitting at my desk

or at my cubicle when we are finally able to go back to work?

**Lynne:** Yeah. Get up and walk around.. And the stretching that you can do while you're standing. And also just to, to relish in the normalcy and the pleasure of having gone back to work. I think we will see it from a very different perspective.

**Becky:** Yeah, absolutely. I appreciate that as well. This next question says, how do we balance staying informed, whether it be on our disease or the coronavirus without being on information overload? Can watching too much news or reading too much about what's going on affect our mental health?

**Lynne:** Yeah we touched on it a bit briefly when I made some comments about Facebook and YouTube just sort of be careful what you watch and be careful with doctor Google as well. It's always a trade off. We want to be informed and yet we don't want information that's going to overload us or stress us out. So it's a constant battle during the day because it is a situation that's changing almost hour by hour. I don't know about where you are situated but in Toronto now all of the city parks are closed off, all the equipment is closed off the ballparks, etcetera. So it's changing hourly. So you need that information, but you don't want to be overloaded. So I would say know yourself and before you go to bed is not the time to do it. Maybe when you get up in the morning and perhaps one other time during the day. And also be careful of your sources, stick to trusted sources. In Toronto and Canada, we use public health. That's our source for what we can and cannot do, literally. So find your trusted source and access it in a way that feels comfortable but not before bed.

**Becky:** Great, I appreciate this. So our next question says, can you share some tips and tricks on how to find the positive in scary situations like getting a diagnosis, starting a new treatment, or even a pandemic? So one thing that I heard recently on the news, and I'll just mention this while you're thinking there, is one of our newscasters pointed out a quote by Mr. Rogers and it's like when things get scary to look for the helpers cause the helpers are always there. And that's one thing that we're really working on with my kids. Like they hear things and they hear a little clips of the news but we try not to watch too much with them around. But we tell them that there's doctors and nurses, we have a lot of friends that are healthcare professionals and that they're doing everything they can to help everybody that they can. So that's my tip, going back to my childhood with Mr. Rogers and I know in Canada there's Mr. Dressup too, and I'm sure there's good quotes from him as well.

**Lynne:** Absolutely. Yeah. And I think you know, getting a diagnosis of pemphigus and

pemphigoid and also trying to deal with how to make sense out of the pandemic is challenging at the best of times. But you know, we are immunocompromised and it's tough in this situation. So extra reason to pamper yourself and get others to deliver you groceries. Generate the Goodwill in your family they'll feel better for it. See if you can get help with grocery delivery. It's a good time to focus on things that matter most like relationships and connections to try and foster those during the times when our physical movement is restricted and to try and enhance those connections by reaching out to people. Many people are saying now that they spend more time and are more connected to more people than they were prior to the pandemic so that hopefully is a good feature because we are creatures that are programmed for connections and attachments. So to try and foster those while looking after yourself, you've got a good reason to pamper yourself now. I mean, the term that we've been using here is shielded. If you're immunocompromised, you should be shielded, which means that you should limit your exposure to risky health situations in terms of COVID. So things like grocery delivery, etcetera, see if you can get help around them if you can, or to do it in a way that minimizes your risk. So to look after yourself, be kind to yourself.

**Becky:** Yeah, these are some great tips. And this question might play into kind of that as well. This person says that they've heard that they need to check in with themselves. How often should I do that and what are some questions that I can ask myself to evaluate my current health and mental wellness?

**Lynne:** Well, you know, that's a good question too. And I'm thinking of the day, a normal day during the pandemic, your emotions go up and down. This is okay, this isn't okay. This is okay, this isn't okay. This has happened and that's going to happen and it all has an impact on the way you're feeling. So it's inevitable that in days like we're going through the way you're thinking and feeling will go up and down. I guess the best way to try and have a perspective on it is when you start to feel out of control, to try and find your thoughts and feelings, to try and find a way to dampen it down. To do the things that will get your prefrontal cortex back in control, to do whatever you find will help you do that. So the walking, the yoga, the relaxation, the mindfulness, the cooking, the baking, the reaching out to a friend, a grandchild, a helper, a peer coach at IPPF, whatever it's going to take to get you back in control. Because it isn't you. We are going up and down every day, sometimes every hour. So it's normal. It's almost normal that we would experience that up and down. When we need to dampen back is when we start to feel overwhelmed and out of control. That's when we need to step back and say, Whoa, that's too much for me right now. I need to do something about that.

**Becky:** Great. Thank you. Our next question comes from Carol and she says she has an ultra

rare form of muscular dystrophy and has learned to be accepting and calm as a result many years ago. I am obviously not happy about now having MMP or mucous membrane pemphigoid but I'm not angry or upset. Is there something wrong with me?

**Lynne:** Just to clarify, is there something wrong that you're not feeling angry or upset?

**Becky:** I think that's what she's asking.

**Lynne:** Well, it sounds like you've developed a healthy coping strategy for dealing with the chronic illness that chronic illness card that you've been dealt in life and you happen to pick up another one and you went, oh, I know how to deal with that. Whatever has been working for you when you picked up the first card out of the deck is helping you in picking up the second card out at the deck. More power to you. And it would be lovely to hear what is helping you, but certainly I think a positive reframe for you on this one would be I've developed a coping strategy that works for me when I'm dealt with life's challenges and blows. I'm dealing, I figured it out with the first card and I'm dealing.

**Becky:** No, I think that's a great point. That there is some healthy coping going on there and that while things may not be the brightest right now, you know that there can be a bright spot and there are ways to deal with things and I think that's important for all of us, no matter what's going on in our lives. To realize that this is a moment. It might not always be this way. Sure it could get worse, but it definitely can get better as well.

**Lynne:** And just to add that, I think you've also discovered that bravery is in order and you're acting very, very brave. Very bravely and more power to you.

**Becky:** Absolutely. Our next question has to do with social distancing. It just says that since we are practicing social distancing right now, do you have any suggestions or ways I can stay connected with my family? I'm a social butterfly and I feel like I'm sinking into a slunk because not just getting that normal social interaction that I normally do.

**Lynne:** Right. Well, I think that maybe something that would work is setting up a routine with all the people that you normally see and do it virtually on a schedule. If you normally have coffee with X and lunch with Y and you know a drink with a P, to set it up and to do it virtually.

**Becky:** That's a great idea.

**Lynne:** Yes. It might help fulfill a social need, and space it out and also give you things to look forward to during the day so that the day isn't sort of a void, but it has a structure to it. A social structure. I think that's what you're looking for is a social structure. So to be able to set it up virtually.

**Becky:** Great. Yeah. Our next question kind of has a twofold and it says that I'm on my phone constantly whether I'm talking to people or visiting multiple social media sites. I've noticed in the past couple of weeks it's like I can't even walk around my own house without my phone in my hand. How can I break this curse?

**Lynne:** As I speak into my cursid phone.

**Becky:** I notice it too, that just trying to be connected. That I want to be on social media sites or doing more FaceTime. I think that this is a great time with my family as well. And I kind of feel like my phone at times kind of gets in my way of truly remembering and being with those I'm currently with.

**Lynne:** Right. Well I guess it's like everything, you know, it's the good news and the bad news. And I think just acknowledging that smartphones are a blessing and a curse. But we are connecting through them. It's like they are our lifeline, our umbilical cord at the moment. And I think it's like anything, you know, like when you go to a family wedding or a convention or anything, to know when you're on social overload. It's the same thing really. And to know when you need your downtime, to know what times of the day you need your downtime and put your phone on do not disturb. And set limits if you feel better doing so. But I think Becky, you raised an interesting point that perhaps the guilt that people feel when they're on their phones when their kids are around or their partners are around or they should be working or whatever. But it is a lifeline for us. I guess it's always a trade off between being a lifeline for us and being an overload for us. And that's always the balancing act. When is it overwhelming us and when is it helping us? And to be able to determine when that happens. If we're always dismissing our kids cause we don't have time cause we're always on the smartphone to be able to determine when you can and when you can't or when you want to and when you don't want to. You can even determine it with your kids depending on their ages of course. So the blessing and the curse.

**Becky:** No, that's great. This next question I think kind of gets to a root issue and it says how much of my anxiety is me and is it possible it's an issue with my genes? Other family members also have anxiety and depression issues.

**Lynne:** That's an interesting question. So there is a genetic component. There can be a genetic component to anxiety and depression. I'm not that familiar with that particular area, but I do know that that does exist. And it's the whole nature versus nurture discussion. How much of it is our genetic makeup and how much of it is our environment and where we grow up, and the genetic makeup that we have. And I really can't comment much more than that on it. Not really my area. I don't know that much about the genetic composition of these various issues.

**Becky:** Well we appreciate that. You know, just having that information and, it's fine if there's a part of the question that you don't feel comfortable answering, you just let us know. We're very fine with that. Our next question is that as a family member and a caregiver for somebody with pemphigoid, what are some signs of mental health or mental illness that I should be aware of and watching for?

**Lynne:** So look for differences in behavior, real changes that you notice. Are they more withdrawn? Are they more irritable? Are they more sad or down? Are they having trouble sleeping, getting out of bed, going to bed? Are they eating more, sleeping more, eating less? And then just to acknowledge that what we see without judging or criticizing because nobody wants to be judged on the way they're thinking or feeling. I don't think that would be helpful. But just to acknowledge that you notice a difference and you wonder whether they would want to receive some support around that from a professional.

**Becky:** Oh, great Lynne, that's some really great advice. Our next question says I was prescribed a medication for depression a year ago for some issues that I was having and I am feeling a lot better now. Does this mean that I'm cured and I can stop taking my medication?

**Lynne:** Well, the fact that you're feeling better is great. It means your medication is probably working. I mean, again, I'm not a doctor, I can't say, but that's the hope for goal with the medication and without any other factors. Let's assume that the medication is helping you, which is the desired effect. So no, always check with your doctor before stopping. There can be very many adverse effects to stopping a medication cold turkey. Any change in medication has to be done in conjunction with a medical professional because there can be a physiological impact on the way that you feel and the way your body adjusts to the change in medication.

And actually if you are feeling better, it probably means it's working and you shouldn't stop without seeing your doctor.

**Becky:** Great. Great advice Lynne. Thank you so much. What are the differences between counselors and psychologists and psychiatrists and how can they help me through difficult periods that I'm having?

**Lynne:** I know it's a confusing field for people. I'll tackle it the best way I can. So a psychiatrist is a medical doctor who has gone through the various years of medical school and professional training, specialty training in psychiatry. And is board certified, so they usually prescribe. In Canada, the way it works is they prescribe medication, although family doctors do as well. And they monitor medication and will provide assessments and diagnoses. Talk therapy because they're in such demand some do, some don't. I don't know how it is in the States. Psychologists are PhD level university graduates who have taken a psychology training and are regulated by the association of psychologists in Canada and in the United States. So there are PhD level practitioners. In Canada they don't prescribe medication. In Canada the only ones who prescribe are medical doctors either GPs or psychiatrists, I don't believe psychologists prescribed in the States.

**Becky:** I was going to say I don't think so either, but I don't know that for a fact.

**Lynne:** Yeah, I would have to get that clarified. I know in Canada they don't, but the psychologist can diagnose in Canada. Social workers like myself are masters level practitioners. And we are a regulated health professional in Canada, which means we belong to a regulatory body, we're registered, we have numbers and for insurance purposes if you have extended health benefits, you can generally claim for a certain number of sessions with a social worker and with a psychologist. But psychologists like myself do not prescribe or diagnose but we can treat. We can deal with the garden variety of issues. And then there's psychotherapists who really are masters levels practitioners as well as very similar to social workers.

**Becky:** Great. That's a lot of great information right there. We have time for one more question and it's to be a mouthful so if you need a little bit of time to think about it, that's okay. How do I find a mental health professional who's right for me and are there any interview questions that can help me find the right person for me?

**Lynne:** Yeah, it is a really good question. Much of the research shows that what helps most in talk therapy is the relationship, is the connection with the therapist. Regardless of what the

designation is, regardless of whether it's a psychiatrist, the GP, a psychologist, a social worker, a psychotherapist, a peer coach, it doesn't matter. It's the connection. So I would certainly want to look at things like if you wanted to ask them, what kind of approach do you use? Do you use cognitive behavioral therapy? And let them talk a little bit about how they would work with you. Most practitioners will give you certainly a free phone consultation or an online consultation, at least here they will. So that you can determine if there's a comfort level with the way they work and what your needs and goals are.

**Becky:** Great advice.

**Lynne:** Yeah. Ask how they work.

**Becky:** Well thank you Lynne. That was a very quick hour for us, so thank you for being on the call with us today. I know I learned a lot and I really appreciate you taking the time out of your day. I also want to give a huge thank you for everybody who joined us on the call this morning or this afternoon. And a big thank you to Genentech as well for making today's call possible. I do have a few announcements before we go. Our next patient education webinar will be on April 15th with Dr. Ron Feldman from Emory University to answer your questions about pemphigus and pemphigoid and side effects. We also need your help to continue to spread awareness about pemphigus and pemphigoid. Our awareness program aims to accelerate the time it takes pemphigus and pemphigoid patients to get diagnosed by stressing the importance of a biopsy. Your tax deductible donation will support our Biopsy Saves Lives campaign that will educate and encourage dental professionals to consider a biopsy sooner in order to diagnose patients faster. We're counting on you to make a difference in the lives of patients with pemphigus and pemphigoid and their families by helping us accelerate diagnosis times. Donate today and help us reach our goal of \$15,000.

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!

Lastly, if you have a question that didn't get answered on the call, I know there might be a few 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 a survey following this call. Thank you everyone, goodbye.

**Lynne:** Goodbye. Thank you.