

Our Speakers this evening are Janet Segall and Ivana Mitchell. Thank you for joining us today! The call today will focus on mental health and chronic disease like pemphigus and pemphigoid

Ivana Mitchell holds a Masters Degree in Social Work and is a Registered Social Worker in Toronto, Canada. She provides psychotherapy in a primary care clinic and in private practice, assisting youth and adults struggling with a wide spectrum of challenges including: abuse, trauma, loss, relationship problems, chronic illness, and mental illness. Ivana is a Certified Daring Way Facilitator, offering a psycho-educational workshop created by Dr. Brené Brown, aimed at helping individuals embrace vulnerability and live with connection, compassion, and courage. Her education and training came in handy when she was diagnosed with Pemphigus Vulgaris. Through personal and professional experience, Ivana is aware of the challenges that accompany chronic illness, as well as the mind, body, and soul practices that may assist and empower those with an autoimmune disorder to live a wholehearted life.

Janet is the Founder of the IPPF. She was diagnosed in 1983 and started the Foundation in 1994 with the express purpose of giving people living with this very rare disease a place go to find information and others also living with pemphigus. Janet graduated with a Bachelor of Science degree in Psychology. After college she worked at Pilgrim State Mental Institution on Long Island. Upon moving to San Francisco she volunteered at the San Francisco Mental Health Department assisting the psychiatrist in the psychodrama group. She also worked at the Women's Refuge in Berkeley, CA. In 2009, Janet received her certification as a hypnotherapist and began working with the Foundation as a Health Coach in 2015.

Becky: Carol is asking, how do I know if the person I'm caring for is sad or depressed?

Ivana: That's a really good question and I assume this is someone who is asking on behalf of someone who might have a chronic illness. It's hard to know what the distinction is a lot of the times, because sometimes the symptoms can overlap. What we are always looking for is anytime you have concerns about someone you really care

about their mental health and well being. One of the first things I suggest for people to do is visit their family physician. Just to get a check up and see how things are going, and they can do an assessment and their own clinical judgement of how the person is doing and how are they managing and whether or not they fit the criteria of clinical depression. Sadness is one of the primary emotions that we have. It comes up when we need comfort, it's very adaptive and it's very healthy to experience sadness when something comes our way that we did not expect , something that we have that we don't want. We know that when it comes to chronic illness that certainly clinical depression can follow because there are a lot of stressors that are places upon us with chronic illness. A lot of the times they look for symptoms that have last at least six months or more. Those include things like- feeling really pessimistic, or hopeless, feeling really worried, worthless or helpless. Any type of extreme physical fatigue, mental fogs or trouble concentrating. There is a huge red flag if there are any thoughts of suicide or self-harm, or thought that tend to end one's life. An overall consistent sad, or empty feeling. People who have depression usually say that they feel really empty. It is something that needs a clinical sorter that needs to be properly diagnosed or treated. Certainly speaking with your family physician if there are any sort of concerns you may have to see whether or not that person fits the criteria for clinical depression.

Becky: Shari asked- Is there a strong connection between chronic inflammation and dementia?

Ivana: That's a really good question. I as a psychotherapist would not be able to answer that with 100% certainty. That's something that a neurologist might be better at and more equipped to answer. I provide talk therapy and workshops for mood more so than cognitive type of disorders such a dementia. But it is very interesting, any type of inflammation in the body. I've read so many studies about how it affects lots of different areas in the body- physically, emotionally and certainly cognitively as well. That's something I would certainly ask a neurologist, I am not equipped to answer that question.

Becky: Kate is asking a question and she wants to know- What is the best way to approach a friend or a family member to ask if they would be involved in my care? I'm independent and head strong, how do I know when I need to ask others for help?

Ivana: I almost feel like there needs to be a support group for us strong willing, independent people who all of a sudden need help. We all know that asking for help is such a vulnerable thing. In this culture I know that I can say that we romanticize that I don't need anyone, I can go it alone and we are so willing to seek support and get help when we are really young and when we are really old. But for most of us in the middle state we really suck at asking for help because we want to be independent we don't want to rely on anybody, we don't want to burden anybody. I can genuinely say that professionally and personally, having a support team is incredibly important when you are dealing with something as a chronic illness. Especially if you've just been recently diagnosed or if you are currently in the midst of treatment. It's incredibly important to have people around you, even just a handful of people who are able to be there for you that can potentially drive you to an appointment, that can make you a meal, that can help you figure out how to talk to your insurance company and something that's really scary for you. All those things are just to be a shoulder you can cry on when you are having one of those days. I totally connect to and relate to the idea of- It is so frustrating, I've been able to do this on my own and now all of a sudden the rug is pulled from underneath me and now all of a sudden I need help. I find that asking for help, not everyone can be in your support section and so we need to be very clear on what it is you need. I certainly had a couple of friends who were fantastic with empathy and that if I was having a hard day they didn't try to make it better or try to silver line it for me but they just said "Oh man, that really sucks, I'm so sorry that you are going through this". I certainly had people that, I had a friend who was a personal trainer and she would come over to my house and she would kind of work me out so that I was working my weight management with prednisone. I had my spouse who was a really good support who came with me to a lot of my medical appointments. It's really helpful to be able to rely on people who have earned the right to be there for you in those really tough moments,

and knowing that asking for help is a huge act of courage but it's not a sign of weakness. We all need to give ourselves permission slips to just be human, that we all need help from time to time. It's lovely to be on the other side, and now that I'm in remission and feeling really good, I'm on the helping side and it feels really good. I can also genuinely say that I learned so much about myself and about the work that I do from needing help at the same time. Be really picky about who you include in that circle support section those are really special people that could provide emotional support but also support with just everyday things and be courageous to ask for that support if ever needed and also tell them "thanks".

Becky: And I was going to add something...

Janet: Excuse me Becky, I am online

Becky: Oh hey Janet, how are you?

Janet: I'm good thanks.

Becky: Great, welcome to the call. We were just discussing a call and Ivana gave us a pretty good answer about what is the best way to approach family and friends to be involved in my care, especially if I am independent and headstrong? How do I know when I should be asking for help? Would you like to add anything to that?

Janet: No, I listened to what she was saying and I absolutely agree with everything she said. There really is nothing that I can add to that at this point.

Becky: Great. Well I was just going to say...

Janet: I was just going to say that it is really important not to be afraid to ask for help even if you are headstrong. Not being afraid, take that risk because it is worth it.

Becky: Absolutely.

Ivana: I would say what really helped me as well was being really clear about what I needed. So first you kind of have to know, within yourself, what is it that would be very

helpful for me. Well what is it that I need? And then be very brave to ask for that and say it in a very clear way that the person can say “Yes I can do that for you” or perhaps they can’t for whatever reason but then you know for sure. That is very vulnerable and it is what makes it incredibly courageous.

Becky: Absolutely. I was going to add to that too just in my own experience. I had a friend who, from the time I was in the seventh grade, could make me laugh no matter the situation, no matter the tense and there were times I wanted to crawl into my shell but I purposefully reached out to her so she could make me laugh and make sure that I did not crawl too far into that shell. That there was still that humanity, that normalcy that we always have had in our friendship. That give and take where she could just absolutely, positively make me laugh and that was really important to me.

Ivana: Yeah, we need those connections when we’re really in the deep, pit of struggle. Somebody that can sit with us in that space. And I can also say that for some people, what I find really sad is sometimes people see me for individual counseling or psychotherapy and they’ll say, “I don’t have a big support system” and that’s really tough when we’re having a really hard time because those kinds of relationships and connections take a lot of time to build and nurture. So what I encourage people to do, is if you don’t have that support person, especially emotion support, if you don’t have that from family or friends then try to see if there is somebody you can see professionally that can provide that for you because we all need somebody that will provide a non-judgemental really safe place where we can be with our feelings. And sometimes family and friends do that for us and sometimes they can’t and that is something that most of us need when we are going through a hard time.

Janet: I also want to say there is the IPPF and there are support groups all over the place and peer health coaches you can talk to. So there is support out there if you are not feeling comfortable about asking someone you know, there is support out there through the foundation.

Becky: Great, you are absolutely right Janet, thanks for giving us the plug there. Hannah asks, what are some common mental side effects that my dad might experience once he starts treatments on prednisone or some of those other treatments? And what are some things I can do to help him combat or relieve some of those mental or physical side effects?

Ivana: Janet, do you want to take this one?

Janet: Side effects of Prednisone can be real difficult because what happens when you are taking Prednisone is that everything speeds up. It's like being on speed a little bit because the way it works is you are in a fight or flight situation a lot. So that until your body gets used to the Prednisone someone can be very curt so you have to watch those signs and the best way to support someone with that would be to listen to what they are saying, try not to get angry and realize that a lot of that is the drugs, and these drugs can cause these kinds of side effects. It is difficult for the caregiver often, so it is important for the caregiver as well to find ways for them to deal with the whole issue of this, someone having to take these drugs. There are a lot of different things going on here so, that is my suggestion.

Ivana: Yeah, definitely. My goodness. Prior to being diagnosed with Pemphigus and needing to be on Prednisone I supported in my naive healthy state, I supported a few clients with other chronic illnesses, other autoimmune diseases, who were also taking high doses of Prednisone and they are actually referred to me because they had "anger issues". So of course I read up a little bit about what Prednisone is and what it does and so I worked with them on strategies on how to be able to tolerate it and some of the anger because there is not much you can do about it a lot of the time but also how to diffuse that sensation. Then I remember when the dermatologist said, "Systemic treatment has to go, this cannot be treated locally". I just started crying uncontrollably when he said the Prednisone word because that was the thing I was scared about the most, seeing the impact that it had on clients that I used to work with in the past. It is certainly a drug that, I genuinely felt possessed for a lot of it until the dose was low.

There are certainly a lot of similarities, I know a lot of people get very angry but that was not my experience. So on the one hand there are certain similar side effects that people have and on the other hand you may surprise yourself. I became incredibly sensitive to other people's energies. When I would walk into a room I could feel what other people were feeling and I had never felt that before in my life. It took a couple of weeks to figure out that that is what was going on. So I had a different emotional response than most people and I agree with everything that Janet said. You really have to figure out what are your strategies for yourself. But also as a caregiver, how do you disconnect from that a little bit and say, "this is not the person that I love, this a medication that they are going through", and also do your own selfcare. Because it is really hard to see your loved one go through the rollercoaster that Prednisone gives us.

Becky: Absolutely and I am going to ask this question now because it follows up with what you are talking about. This person asked, from your experience what is the best way to approach talking to a family member or loved one about their mental health state when they are already dealing with other medical problems? When is it okay for me to step in and tell them "They just haven't been themselves?"

Ivana: I find that it is a very vulnerable or delicate conversation because we want to be able to approach it from a place of curiosity and a place of concern and a place of love. Sometimes we really don't know how it is going to land but we don't want to approach it from a place of judgement, anger, or frustrations so knowing that you as a caregiver, you're in a good place and in a good moment, that is a really good indicator of when to be able to have that conversation. Anytime I have to have a very vulnerable conversation I use the sandwich method. I start off with a positive and say something like, "I love you very much, I know that you have been going through so much difficulty and my goodness I have been so impressed by the way you have been able to tolerate all of this that has been thrown at you, and then you insert the negative and say, "And then at the same time I am having some concerns about some of the behaviors you have been showing in these last couple of weeks. It really concerns me because I really

care about you. Is there anything that I can do? How are you feeling with all of this? Is there some way we can get you some support”? So always doing a positive, negative, positive is something that I do in my personal and professional when I am giving someone bad news or asking for what I need or letting people know how I feel. We want to be able to approach it from a place of curiosity to sort of figure out what is going on but always from a place of love and concern, not judgement and frustration because they are going through enough.

Becky: Yeah, I think that is a great tip. Janet do you have something you would like to add to what Ivana said?

Janet: No, I think Ivana put it right out there. You have to be really careful and gentle about how you approach certain things with certain people. You have to know the person you are talking to and get a sense of when they might be ready to hear some information about that.

Ivana: There are some great literature and books out there about empathy. Empathy is a skill that can be learned. It is how to be able to connect with people, how to be able to listen to them without have our own perspective and our own judgement. Be able to really pay attention to how it is they are feeling and communicate that back to them. A lot of the times I work with caregivers, I work a lot with empathy skill and how to strengthen that so that the person you are supporting can really feel seen and heard and validated. So I can always send Becky a list of books and videos on empathy that are really helpful for anyone who is wanting to be in a relationship with people.

Becky: That would be great Ivana. I would like just to have that. I do not have a need for that right now but that’s always great to have as a reference in your back pocket, so I would appreciate it if you would share that with me and if anybody else in our community that is listening to this call please contact me then I will pass that along to you as well.

Ivana: Perfect

Becky: Our next question comes from David and he asks, when should I seek the advice of a mental health professional? I feel I am doing well now, should I wait to see how this goes or should I see somebody now?

Janet: That is an interesting question because sometimes you just have to go with your feelings, what you feel. If you feel like you need to go see someone now, then you should go see somebody. If you feel like you can wait, there is nothing wrong with asking for help for yourself. There is nothing wrong with seeking that and realizing that you have to be ready and knowing when the right time is for you to ask for that help.

Ivana: Yeah, it is a really individual decision and choice. For me personally, I am biased since I do this for a living so I genuinely think that most people benefit from talk therapy especially when we are going through a hard time and working with something that is chronic. There is so much uncertainty and unknown attached with to it but you have to figure out what is a priority for me. Am I functioning and how am I managing, how am I feeling, how am I doing? Is this something I can afford, because finances can also get in the way. And so it is a really individual question for yourself and it takes some time usually to find the right fit when it comes to meeting with a therapist. You want to find someone that will make you feel safe to explore some of these difficult situations and feelings that you may be having. But if you are doing well, then amazing and keep it up. But if you are not then please ask for help because even for myself, I am a registered psychotherapist, I do this for a living, I certainly saw a therapist last year when I was finishing up my treatment and it was so helpful to be able to grieve the loss of the healthy me that no longer is. Even though I was managing really well and doing fine I still really wanted to work on some of these unresolved grief feelings that I was experiencing and it was so helpful to have even those 5-6 sessions to be able to work through that. So there is no shame in asking for help at any stage of the game.

Becky: I just want to share a story, I have a friend and for their 20th wedding anniversary she and her husband went to marriage counseling. They weren't having any issues but she just wanted to make sure they were "normal" and had great lines of

communication that were open. It was one of those things where the therapist thought it was really neat because they were a healthy couple but somebody was coming to them before they were in crisis. They ended up going for just a few sessions just to work on a few minor problems but that therapist being excited made them kind of excited to talk about more things with each other. So maybe that might help somebody out there to answer that question as well, that it is perfectly fine if you are feeling fine to go and make sure. A follow up question to that is, how do I find the right professional for me? Are there any good interview questions or a website that I can go to? And what is the difference between a counselor, a psychologist and a psychiatrist? So a lot wrapped up into a little question.

Janet: Ivana should take this one.

Ivana: Thanks Janet. So certainly finding the right fit. There are so many different modalities and types of therapy, it's a little overwhelming. So I practice a few of them but I certainly, oh my goodness, there are so many things to learn because even though they all have similarities they also have differences in the way they approach emotion and see how do we work with them. So a good website for individuals to check out is <https://www.psychologytoday.com/us>. It is for people in the U.S. and Canada to access, I am not sure in other countries, but you can enter your postal code if you are in Canada or enter your zip code if you are in the states and it will pull up a list of therapists in your area, with their profiles and their bios. You can read more about them and what they are about and you can get a sense of what their approach is in terms of how they sell themselves. A lot of therapists will have a website that you can also check out and you can see what kind of vibe you get from them. I am biased in the therapies I employ. I utilize cognitive behavioral therapy, dialectical behavior therapy, and something that I find incredibly helpful is emotion-focused therapy. But certainly there are so many other things out there that are really helpful for individuals and most of all any sort of research that I have read in terms of what kind of therapy is most useful, they all say one thing. And that is, the relationship that you have with your therapist far outweighs the type of

approach they have. So if you find that your therapist works for you and is really there for you feel that you are comfortable and safe with them then that will make any approach that they use more effective. Most therapist will offer a free phone consultation that you can talk to them over the phone and questions such as, “have you ever worked with people with chronic illness before?”, “what is your approach?”. You want to make sure they have availability, and what their cost is as well. So those are some of the questions. They will also ask you questions like, “What do you hope to get out of this?”, “Why are you seeking the support now?”, “What does a successful experience look like for you?”, “What have you done in the past?”. So those are some of the questions that I ask some of the people when I do the phone consults. And then it takes a few sessions. Don't be confused if you are not 100% sure after the 1st or 2nd time. Sometimes it takes a few sessions to get into a groove and if it doesn't work, it's okay look for somebody else. Difference between, and I can speak in terms of Canadian terms, a psychologist is somebody who has a Ph.D. in psychology and there are talk therapists, so similar to counselors or psychotherapists, like myself, with more education. Often times they have more experience but then can be a little more pricey. Registered social workers or registered psychotherapists, they also provide talk therapy but they do not have a Ph.D. but they do very similar work and are sometimes more cost effective. A psychiatrist is a medical doctor who specializes in mood disorders. A psychiatrist is usually connected with a hospital and they are responsible for diagnosing and treating mood disorders such as depression, anxiety, personality disorders. They are medical doctors so they are the only ones who can prescribe medication. So I hope that answered all of those question and you let me know if I missed something.

Becky: No, I think you did great. Janet, do you have anything else to add?

Janet: No, I think that was perfect. Yeah, the distinctions can sometimes be hard to tell but what we are finding now is the psychiatrists, basically what they do is they talk to you for a little while and then they give you drugs. So you go to a social worker or

psychologist in order to get... also social workers don't necessarily... I don't know, I think Ivana covered it all.

Becky: Well great, Marjorie is asking, how do mental health professionals help with patients to deal with chronic pain?

Janet: Well you know, I think there are different ways to deal with pain. There are medications that somebody could take that might help and there is also integrated medicine. A lot of places do what is called integrated medicines, you can do meditations, and hypnotherapy and acupuncture and different ways to help deal with pain. If you don't want to take drugs there are other methods like I just mentioned and if you need to take a pill every once in a while it is allowed. You need to find a way to deal with the pain that fits you best.

Becky: Great, thanks Janet. Ivana do you have anything you would like to add?

Ivana: Yeah, I agree with everything that Janet said. I think that sometimes pharmaceutical intervention is helpful depending on what the source of the pain. I have worked with patients with fibromyalgia, which another difficult to treat chronic condition. And I agree with what Janet said that more holistic therapies are really helpful such as meditation and mindfulness. There are specific groups designed for people with chronic pain because what we know is that when we resist the pain, we tense up and the pain gets worse so learning some strategies to try and relax the mind and the body will actually allow you to be more tolerant of the pain. Acupuncture as well as hypnotherapy as just talk therapy as well have been really effective with managing chronic pain but it is a really difficult symptom or side effect sometimes because it will certainly have an impact on use emotionally. So I hope that whoever asked that question gets whatever support they need because that is a really hard thing to live with.

Becky: Great, thank you. What are some alternative treatments to help combat the mental pain associated with having a chronic disease besides from medication?

Janet: You know that is kind of what I just talked about. There is meditation, can really help and mindfulness. Not holding your breath is a really important thing when people are in the pain they tend to hold their breath, and to breathe and just keep breathing and think positive thoughts. A little like what hypnotherapy does there are different ways that you can deal with that, with the pain. There was something else that I had on my mind and it slipped out right now but maybe if Ivana takes this I'll think about it.

Ivana: Come back at me anytime. Yeah, there are so many things out there that are really helpful and I encourage people to really explore and to sort of figure out what really works for them. One of the things that really helped me was journaling. Journaling has been found to have a really good impact for maybe those people who don't want to talk to somebody or can't afford a therapist. I created a blog and every single day no matter how or what kind of condition I was in, if I was having a really great day or I was having a really awful day, I would make sure that I planted my butt in that seat and for even 5 minutes even 15 or sometimes 30 I would make sure I allowed myself the time to be able to put some of those thoughts and feeling on to my blog post and it always made me feel better. So now it has been so fascinating, that it has been, my treatment was the majority of last year and so it has been really interesting now to look back and see what kind of state of mind I was in and what kind of state my body was in. Journaling is something I highly recommend even if you just write, "Today I feel, today I'm going to, today I'm grateful for" anything like that, anything that sort of habitual kind of ritual can be really helpful for people. Art is incredibly healing. If that means painting, if that means dancing, if that means singing, whatever the heck makes you creative. I took a few months off of work to really be able to focus on my own healing and I really love to knit and crochet so I had a couple of friends who were having their babies and their babies were having their first birthdays so I knitted up a whole bunch of blankets and hand-puppets and all sorts of fun stuff to really keep my mind focuses on something else, something that I really enjoy. Exercise is really helpful as well, any type of

movement is really helpful. So other than talk therapy there are so many things that we can do, everyday things that can be really helpful for our mood.

Becky: Great Ivana. Just kind of following up, you just mentioned something about exercise and Jimmy says, I know that exercise is important for me not only as a caregiver but for my family member who is a patient with pemphigoid. What are some ways to encourage them to join me in exercise and what are some good exercises they can do that will not be painful for them?

Janet: I think it also depends on their age. There are chair exercises that so people find really helpful if their body is hurting from the drugs. There are chair exercises, there is yoga, mild types of yoga and there is even chair yoga. And there are very minor exercises like riding a bicycle or even at the gym if that is possible, rowing machines. Something that is not too difficult for someone especially if they haven't been exercising. So there are lots of different exercises and encouraging them. You know it is hard to tell somebody else what to do you have to sort of feel them out and find out what they would like, what would be their interpretation of exercise and what they would like to do. Would they just like to talk a walk. So have to find out what it is they want to do and be there to help encourage them. Start out helping them if they want to do that and encouraging them to find a way to help do that.

Ivana: Yeah, I think that certainly having it be sort of collaborative effort is really helpful and helping them really define what are those things that really bring them joy. And exercise, there are so many forms out there so many different ways that we can promote movement and we really want to be able to see, you know what Janet said do we just go for a walk today do we just music on and move around. Where I live in Canada unfortunately we do not have the loveliest weather most of the time. But my husband and I, I said I wanted to make sure that do to the prednisone, again bone loss is a really common thing, weight gain is a common side effect so I made the commitment that unless I was physically not well, I would try and go we have sort of a small gym in our apartment building, that I would try to go every day or every other day.

So he knew that commitment because I put it out there. So a lot of the times we would go with me and then in the moments where I didn't feel like it, physically I was feeling fine but I didn't feel like it we had a sort of signal for him to basically get me off the couch and get me started. And I think there was a moment when he literally put running shoes on my feet when I was still sitting on the couch and he said, said you have to go, because I was physically feeling fine I just didn't feel like it at the moment I just wanted to continue to watch television. So we figured that was what I really needed so there were times I could get up and go and there were times where I just needed a little bit of a push. I was always so grateful at the end when I had that moment where I could let it out physically. So try to figure out what does your loved one need, what kind of support do they need, what kind of rules can you create for them and yourself and how can you be part of that change because everybody needs that support from time to time.

Becky: Great, thanks Ivana. I think you touched on a really good point there about knowing whether it's your friend or your family member or even a spouse and knowing when to push them and how to push them. Is there any advice that you would have or could recommend about how to set up those boundaries with your friend or your support system before you may actually need it, to let them know how far is far enough to push me and where my boundaries are?

Janet: I think communication, you just have to talk. Communication, find out where those lines are, I think that is the most important thing is to find out how to talk to somebody else about it and make sure they are willing to listen. I have had those kind of things with my whole family, having to have boundaries, maybe too many boundaries maybe less boundaries. Trying to find the right balance can be difficult but they are there.

Ivana: And I can speak for most of the people I work with including myself, we don't really get taught how to create healthy boundaries. That we often times think that as women, generally what I hear is to have boundaries you feel really bad, you feel really guilty when you have to say no to people or when you have to set a clear rule of this is

okay and this is not okay but boundaries are incredibly important for self care. They are also incredibly important for maintaining a really strong relationship and so I agree with what Janet said communication is key and being honest but also knowing what it is you need and sometimes we need some time to figure that out for what would be helpful and what wouldn't be helpful. There was a day I was having a really really bad day and I reached out to a friend and I was telling her what a crappy day I was having and she said something like, and this was all over text which is a awful place to have a really vulnerable conversation, and she said something along the line of, you're getting through it and it's so great that they diagnosed it so early, and it was the last thing I needed to hear. And I specifically said that because in that moment I set a boundary to say, you know I see that you are really wanting to help with this positivity stuff but right now what I really need you to tell me is that this really sucks. And I knew that our relationship was strong enough that she could handle that and she said right away, switching gears I am so sorry, yeah that really really sucks. And as soon as I saw that message I broke into tears and it was exactly what I needed that release and somebody got it. I could've said oh yeah you know and agreed with her but it just didn't feel right to me because in that moment what I really needed was for her to acknowledge my pain. So it takes time to figure out what it is that we need. Boundaries are really fluid, they shift and change over time depending on where we are at in our chronic illness but having that open communication and having that person who is willing to support us in that way, also expressing our gratitude. We are still trying to figure it out as we go because we have never done this before. It makes sense that we are not going to be 100% sure of what this is going to look like.

Becky: You know I think you are absolutely right there Ivana, so thank you. And along the lines of communication, just a little personal story I know we have been talking a lot about the more things people can do for me in my time of need. For me a moment of clarity came when I told my friend that it was the first day I woke up without a lesion when my treatment started working and that was a big deal to me but I did not think it would be a big deal to anybody else. And she dropped what she was doing and left

work early and she brought flowers over for me to celebrate, that normalcy. So it was the fact that I communicated that to her not realizing that she would realize the impact but the things that she did for me in return to help me celebrate those itty bitty baby steps in my treatment from dropping my dosage from 80 milligrams to 70 milligrams of prednisone. She made big deals and balloon bouquets for all of these steps. Having somebody do that for me as well really kind of changed the dynamic of having to deal with this disease and somebody else appreciating what a large milestone that actually is when the rest of the world may not really realize it as being such too.

Ivana: Absolutely, because that is so true. That we need individuals when we are having a really hard time and when we are struggling but it is also true that it is so lovely to have somebody you can celebrate those little or big milestones where you can say, "Oh my god I did that" or "Gosh, I hope I never have to be on that level of prednisone again". It can really relish in that accomplishment and also to sort of remind you of how far you have come which is so incredible.

Becky: Absolutely. Matt just wrote in and said, I noticed that I don't want to go out in public lately and I can't tell if it is because I just don't want to be stared at, if I am depressed or if there is some anxiety present. Are there some ways to tell what is going on and differentiate between a depression and anxiety?

Janet: Well I would like to say that it's really important that what's happening with you is okay. It is hard to know how other people are going to react to what is going on with you. I know for myself, when I was first diagnosed I didn't know what to say to anybody. And I ran into somebody in the street and they said, "How are you?" and I said "Oh, I have this horrible disease" and then they ran away. It was very difficult and I was in the store and I had a big lesion on my face and someone said, "Oh did you get hurt, did someone beat you up?" and they thought someone was beating me up at home. But you can't be ashamed of what's happening. I think it is important to know that what is happening to you it's okay, I mean it's not okay, but it is okay. It's nothing to be

ashamed of. You can decide who you want to tell and who you don't want to tell and feel that inside you to know when the right time is to say something to somebody or not.

Ivana: Yeah, I think it is such a vulnerable thing, when we are first diagnosed, when the medication is starting, that we're not yet seeing the results that we want and we don't feel like ourselves, that of course our natural response is we don't want to be around other people. I had a similar sort of experience, most of my PV activity was in my mouth and my nose but even though it didn't come up on my face or my scalp, I still just prayed that from my underground parking to my apartment that I didn't see anybody because it is true that I was going through such a hard time. I didn't want to make small talk, it didn't feel genuine for me to say that everything was fine when it wasn't. So give yourself that permission to be in the space for now, wherever you are in this journey with a chronic illness. To really allow yourself to explore what some of these feelings are, and where they come from and what they are telling you and they are normal. I have not met a single person with a chronic illness who's excited and thrilled and happy and completely managing well. Those people don't exist. So we all deal with it in our own ways. So just giving yourself permission to be human and have these feelings a just be curious about them to see what it is that they are telling me. But if it is something that is ongoing and chronic and it is really preventing you from having a good quality of life then I go back to the answer I had said initially where it might be a good thing for you to speak to a family physician just to check things out, just to see where you are at.

Becky: That is great advice Ivana. I know that when I was going through things, I am one of those strong-willed people too so it was really kind of hard for me to admit what was going on. And I remember going to talk to somebody and I was just crying and told them how miserable I felt and how out of control and how sad I felt. And what a loss I felt because I used to do all of these things and I can't and this just isn't right. It was a key moment for me when my therapist said, "Well why isn't it? Why isn't ok? You have lost a lot." So for someone to give me that permission to feel, but not necessarily to stay

in that dark place but permission to just feel and to sit there and cry was an amazing thing to have happen.

Ivana: Yeah, it can be incredibly healing when someone just gives you permission to just sit with whatever is coming up for you. So I agree that it's something that sometimes family and friends can give us that and sometimes it is a therapist that can say, "Oh my gosh of course it makes sense you are going through all of these feelings, look at all of what you have been through, look at what you are going through. It makes you human. There is a really good TED Talk, it is by a woman named Susan...something, and if you were to go on TED.com and type in Susan and then Emotional Agility, there is a really good TED Talk about it, that I can also send to Becky because now I am blanking on her last name. And she talks about how we're taught to be really positive about things and we are taught to not be negative, just be positive about stuff and how we become really emotionally rigid and what we really need to do is to be able to accept all emotions and there are a lot of other strategies she gives in that TED Talk to have emotional agility. And all of these negative emotions they have sort of a really important purpose, that we do have to tune in to them and see what they are telling us, even though they feel really uncomfortable or painful.

Janet: You know it is very interesting a lot of what you were saying, that people will tell you you are okay all of the time. I had that with my family, when I was sick. They are very intellectual kind of thinkers and not a lot of feelings and emotions come out. So when I was sick and needed some help, I went to my family to talk about it but they don't want to talk about that. They were like, you're okay, you will be okay, don't worry about it, that's what you always hear from family members because they don't know how to speak and sometimes friends don't know how to talk to you. I found for myself that looking at other alternatives as nutrition and looking at things to help myself, finding some talk therapy, biofeedback. Talk therapy, like Ivana said, is perfect. It is really good because you can talk to somebody. You pay somebody money to listen to you and they

are not your family or close to you so there is better perspective coming out of it then looking at a family unless there is somebody who can be there for you.

Ivana: And I piggyback on that one hundred percent because so often I get the feedback with I am with people individually and they will say, "Why can't my spouse, or why can't my mom or why can't my sister or brother say this, this is exactly what I need to hear", and I will tell them I can be your therapist because I am not related to you but if my brother or mother or husband came to me with this issue I would not be able to be the type of support I am for you. And I would actually encourage them to seek support with a professional. That part of what makes meeting with a therapist so great is that they care for you but they are not emotionally attached to you so that whatever decision you decide to make they are going to go home and they are not going to be affected by that. Where as with family and friends it is a lot messier, that they can feel your pain in a very different way than a therapist can. We still can but we are not so emotionally messed. I am pretty sure in the last patient education call I shared the story of my mom who felt really guilty from me having this autoimmune issue that she somehow caused it and I set a very clear but really caring boundary to say, "I love you, I care about you, but this isn't about you and so right now I am really struggling and I can't unfortunately make you feel better about what I am going through but I would really encourage you to talk to somebody about this because of course as a parent, it would be so painful to watch your child suffer and go through sometime as painful as this." And so it really encouraged her then to go out and seek her own help because I could not be the therapist that she needed in that moment to help her feel better about my illness. So I agree with what Janet said, that speaking with someone who it's their, that is their job to support you can be such a healing part of our journey.

Becky: Absolutely, thank you. Rosetta sent a message to me just to fill in about your TED Talk, Ivana. She is saying that it is Susan David who have a TED Talk about Emotional Agility, is that right?

Ivana: Yes! Thank you so much! This community is the best!

Becky: Absolutely, they always pull through for you.

Ivana: Yeah, you always need help. That is amazing! Thank you.

Becky: Well great. Well unfortunately that was a quick hour ladies so thank you for being on the call with us this afternoon.

Ivana: Thank you so much. You know it is always lovely to be able to connect to the IPPF community. It was so lovely to meet so many of you or some of you at the conference last year and I highly encourage, you know this is my plug for IPPF, to connect with your community with support groups and also attend the conference. It was such a healing experience for me last year so I always love to be part of these, so thank you.

Becky: No, thank you. And thank you too Janet.

Janet: You know it is very interesting to me on these calls because I really think that there is a lot of information out there that we can impart from the IPPF. I think that everybody should go to an annual meeting if they can or a support group because seeing other people who have and are dealing with the same issues that you are makes a big difference. When we first started off having the annual meetings people would say, well I don't know if I want to be around people who are sick and have lesions and I don't know if I want to see it but it's not like that, that's not what it is about. It's not, it's positive, it's about finding ways to deal with your disease and to find others who know what you are going through. But it is always really positive. So when that person came to the meeting and after they were finished with the meeting they said, "Oh, I am so glad I went. That is not what I thought it was going to be." And I encourage everybody to go to a meeting or start a support group where they are if they can.

Ivana: I agree one hundred percent.

Becky: Absolutely and if anybody listening is interested in starting a support group in their region where we don't have one, please feel free to contact me becky@pemphigus.org or you can call our phone number as well.

Janet: And even for caregivers, not just for patients. I want to say to me it is real important that even the caregivers have a place that they also talk also with each other. I think that it is important and it can be real helpful.

Becky: Absolutely, thank you. Well it was extremely awesome having both of you on our call today and I would like to give a big thank you to everyone who listened in and joined our call today as well. Our next webinar is scheduled for March 14th and the topic will be Rare Disease Week and advocacy efforts Marc Yale and research updates with Dr. Donna Culton from UNC. Also don't forget to register for the IPPF Natural History Study, a new patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US Food and Drug Administration (FDA). Register today on the IPPF Website under the research tab. And a reminder the IPPF is still looking for Awareness Ambassadors to visit local dental offices. Please click on the Awareness Ambassador link for more information. Lastly, if you have a question that didn't get answered on the call, or have additional questions please e-mail me at becky@pemphigus.org , or call me at (916) 922-1298 x:105, and I would be more than happy to help. This call recording will be send out along with a survey following the call so please be sure to fill out the survey to let us know how we did. Thank you goodnight everyone.
(1:04:57-FINAL)