International Disability Rights Affirmation Conference (IDRAC)

Friday November 18, 2016 - 8:00am- 3:00pm
Saturday, November 19, 2016 - 8:00am - 1:30pm
Sojourner Auditorium, Virtual Ability Island in Second Life®
http://maps.secondlife.com/secondlife/Virtual_Ability/54/170/23

Speaker: Chronic Pain Anonymous
Title: "Panel discussion"

[10:58 AM] LV (lorivonne.lustre): Hello everyone.
Todays presentation is being transcribed so those without audio or who require text only can participate in real time.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

You will see the transcription in Nearby Chat.
Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:
Carolyn Carillon

LoriVonne Lustre

The following initials in the transcription record will identify the speakers:

S = Shyla
IL = Ivy Lane
TJ = TeeJens
DS = David / WCD1002
TH = TammyzHere

[11:01 AM] Leandra Kohnke: Hi I am Leandra Kohnke, in real life, Natalie Björklund-Gordon.
I am a Canadian, retired PhD human geneticist and now a scientific writer.
My first book, Embryogenesis Explained, came out last month.
Gentle became one of my first friends in Second Life back in 2007 and I have been watching Virtual Ability grow over the years with delight and astonishment.

It is my pleasure to introduce our Chronic Pain Anonymous Panel.
The peer support group Chronic Pain Anonymous (CPA) offers fellowship with others dealing with chronic pain in a variety of environments.
CPA made its first appearance in Second Life this year and I will introduce today's panel by their SL names.
Shyla the Super Gecko (KriJon Resident)
Shyla is a published author, editor, blogger and poet. She is also a caregiver.
Ivy Lane (RL: Lee Ann B)
Lee Ann is a successful artist, published writer and a loving mentor. Ivy was created as part of Lee Ann's attending the University of Massachusetts, Dartmouth senior project which needed to be a three dimensional environment.
Teejens is a wife, mom to three grown children and grandmother to seven. Her last place of employment was at a large online store as a Quality Assurance Representative. Some of her hobbies include painting, reading and keeping up with the latest fashions.
WCD1002 (RL: David S) David is a quirky, free-thinking, problem solver with a range of interests, from cooking and reading to gaming. In his professional life, David is a Public Accountant and Trustee for a charity.
TammyzHere (RL: Tammy W)
Tammy was a poor, single mom while putting herself through university. (I can relate to that!)
After graduating, she had some office jobs and ended up in the Chicago building trades. More recently she has been a caregiver.
All of our panelists live with chronic pain.
They will share their experience with Chronic Pain Anonymous in Second Life
Please hold questions for the panel until the end.
Thank you.

[11:04 AM] LV (lorivonne.lustre): <transcription begins>

[11:04 AM] KriJon Resident: Hello. Thank you, Leandra, for your introduction. My name in Second Life is Shyla. In real life, most of my friends call me "PC", a long standing shortened version of my real life name.
I'd like to thank Virtual Ability for inviting a panel of Chronic Pain Anonymous (CPA) members to share at the International Disability Affirmation Rights Conference 2016.
Today I'd like to provide some background on what CPA is, then each of us will share a bit about ourselves as members of CPA, with some time afterward for questions and answers.

As an 'anonymous' group, we do ask, in accordance with our Tradition of Anonymity, that no CPA speaker or member be identified by full name in publications or broadcasts,
Including any new media that might go beyond our documented tradition of press, radio, television, film and the internet.
This is essential to our ability to assist those suffering with chronic pain and illness who may wish to share intimate details of the issues they are facing.
It is imperative that all of us maintain our anonymity so that those who would come to us can feel assured theirs is given the utmost care and consideration. Thank you.

What CPA is can be found in our Preamble. We are a fellowship of men and women (and in virtual worlds, beings of all kinds).
We come together in meetings, one of which is here in Second Life each Tuesday at 10:00AM. There are many others, including face-to-face, video and voice, phone and text meetings.
In these meetings we share with each other the things helping us live our lives with chronic pain and/or illness one day at a time.
We are a Twelve Step fellowship which believes changing our own attitudes can aid recovery. By "recovery" we mean learning to live peacefully, joyfully and comfortably with ourselves and others.
The only requirement for membership is a desire to do just this, find more peace, joy and comfort with ourselves and others.
There are no dues or fees for membership. We support ourselves through our own contributions.
CPA does not align itself with any other sect, denomination, politics, organization or institution. We avoid controversy. We do not endorse or oppose any causes.
This allows us to focus on our primary purpose: Living our lives to the fullest by minimizing the effects of chronic pain and illness in our lives and helping others to do the same.

As a Twelve Step Fellowship, we use the Twelve Steps to assist us in this effort.
The structure of CPA is fairly simple and is comprised of the Twelve Steps and Twelve Traditions, which you can view behind me.

The Traditions remind us that although our individual conditions may differ, we are united in a common cause.

We work to set aside personal differences so we may continue to work together in recovering from the mental, emotional and spiritual debilitation of chronic pain and/or illness.

Both Steps and Traditions are voluntary. Most abide by them because they ensure our ability to both receive support and provide support to each other.

A brief history: CPA was co-founded by Dale L. Following surgery to remove a tumor from Dale L's back, he was left with neurological pain from his nipple line to his toes.

After being advised there was no solution, Dale L. decided to apply his experience with the Twelve Steps in A.A. to his chronic pain.

He worked the Steps and shared with others how they helped not only his alcoholism but his pain as well.

Another man, Barry, who was also using the Twelve Steps for pain, heard Dale L speak, and afterward they met for coffee and held the first CPA meeting.

Soon there were weekly meetings, a website, and approval from A.A. to adapt the Twelve Steps and Traditions to chronic pain.

Within a few years, CPA had many members applying the steps successfully to chronic illness as well. So 'illness' was added to our Steps, Traditions and all our literature.

Dale passed away earlier this year. I had opportunities to do service work with him. I can share he was pretty easy going, thoughtful and of good humor.

I am a member of CPA. I have no position of leadership or authority. No such positions exist.

If we so choose, we may provide service to CPA in various ways. By starting meetings, filling board positions, serving on committees.

In all these, our service is guided by the Fellowship. We perform tasks, address business, create literature, and so on, in service to the Fellowship of today and tomorrow.

I provide service to the meeting here in Second Life, but at some point this service will be passed to another.

I am here sharing a bit of general information about CPA with you, again, as a service.

This all comes from our literature, created and approved by the Fellowship.

I hope this provides some idea of what CPA is and how it works. If you have questions, please jot them on a notecard and hold them until after the panel shares.

With that, I'd like to introduce our first panelist, Teejens.

Teejens is a wife, mom to three grown children and grandmother to 7. Her last place of employment was at a large online store as a Quality Assurance Representative. Some of her hobbies include painting, reading and keeping up with the latest fashions.

Teejens' diagnoses include Degenerative Disk Disease, Spondylosis, Osteoarthritis, Fibromyalgia and most recently Peripheral Neuropathy. She is in a constant state of pain and her conditions are growing worse.

She is grateful for the opportunity to speak today and for the support groups that are available to assist her in learning how to live her life with chronic pain.

Teejens will be speaking in voice while the wonderful VAI transcriptionists will post her text. Teejens, the mic is yours.

[11:12 AM] LV (lorivonne.lustre): TJ: Thank you
Hello everyone,
My name is Tee and I live with chronic pain every day, 24 hours a day.
I have been diagnosed with Degenerative Disk Disease, Fibromyalgia, Osteoarthritis and Peripheral Neuropathy.
My chronic pain started in 2006 and has grown steadily worse and now affects every area of my spine. Ten years ago wow, that's a long time and out of those ten, six have been spent in constant pain.
What I am able to accept today, is that these conditions are not going anywhere and over time they're going to get worse. Also, I have been informed that there are no surgical options available, to fix me.
There are however, surgical options available to help with the pain and I will take advantage of those options as they become available.
After many different injections, physical therapies, one failed surgery and being told by more than one doctor that "I would just have to live with it"
I began to search for some different options to assist me in learning to live my life with chronic pain.

My search led me to Chronic Pain Anonymous, and I decided to try one of the phone meetings that I found listed on the www.chronicpainanonymous.org website. That was May 1st 2014. I was hooked from the very first meeting.
I went on to order Stories of Hope and could relate with every story that was printed in that book. So I started attending some of the phone meetings faithfully and after a time started attending the online meetings.
About nine months after finding CPA, and after a failed procedure that was causing me more pain, I went into a major crisis. I was not able to move physically and I felt frozen emotionally.
All I knew was that my life was going to have to change.
The simple fact was, I didn't know how to live with the physical pain and I also didn't know how to live with how I was feeling emotionally that was a result of being in Chronic Pain, for so long.

My favorite book from Chronic Pain Anonymous is Stories of Hope and there is a story on page 78 that could have been written by me. I didn't write it, but I could have.
This story tells about an individual who is trying to control a life that has become unmanageable, due to chronic pain and illness.
This individual goes on to say, "No matter how much I kept trying, the situation did not change." "I could see that all my striving was not helping,"
This individual was trying to keep up with everything, just like I was. Chronic Pain Anonymous has given me the gift of the 12 steps. I'm familiar with these steps and with the miracles that can be produced in my life by working them.
Another gift that CPA has given me is knowing, there are others who are just like me. Today, I know that I'm not alone with my pain, both physically and emotionally.

I thought my life was over and in many ways it was, however, due to my involvement with CPA and starting to work the 12 steps I am beginning to realize that I have been granted a second life, a life much different than the one I had before.

Needless to say, my physical pain has not been cured, in reality it has gotten worse. What has improved, is my emotional pain and I also have a new spiritual outlook.

I've just started working the steps of Chronic Pain Anonymous and what is offered to me is a new way to live with my chronic pain and that is what was needed, since my old ways weren't working anymore.

While my physical pain has been relatively easy to accept, what has not been so easy is accepting my family's reactions to my chronic pain and the decisions I have made in how I deal with it.

Yes, I am still a wife, mom and grandma however, being in constant pain has changed me and they want the old me back, the me I was before chronic pain.

One of the principles I've learned in CPA is "just because I'm in pain doesn't mean I have to be a pain." This quote is taken from one of our One Day at a Time sayings, that can be found on the CPA website.

When I apply this concept and elect to take the higher road, by showing my family members kindness and gentleness, my relationships with them show improvement. Which means there is less stress emotionally and that is very helpful to my pain levels. Plus my family members are more serene. What I've learned is that this concept can be applied no matter how I feel, even if it's the last thing I want to do.

Before I started experiencing chronic pain I was a woman who worked a full time job, took care of my home, enjoyed my grandchildren and had a full social life. I was really good at attempting to be the woman who could do it all.

So, not the case anymore, on some days I can do a little and on other days I can do a little more. I don't work anymore, so you would think that I would have time to keep a spotless house and have a full social schedule.

Not even, nowadays I get out occasionally and I'm ok with that today. I'm also ok, with wearing my pajamas all day if that's what I feel I need to do. Believe me, by body thanks me for it on days when my pain levels are high.

What has become my greatest challenge, is trying to keep my home neat and reasonably clean.

I have problems focusing on tasks, due to being in pain and side effects from medications. I've learned in various meetings I've attended that learning to pace will help with this.

This means not getting things done as quickly as I want, so learning to focus on what I can do in a certain amount of time, rather than focusing on what I can't do, has been really helpful.

It also helps to remember that it's "progress not perfection"

The other skillset that I have been able to add to my "learn to live with chronic pain goals", is Personal Care. Specifically resting, since I always want to overdo it.

There are a few readings regarding rest in Stories of Hope. By the way Stories of Hope can be found on the CPA website, if I haven't mentioned that before. Also, one of the first women, I spoke to from CPA highly recommended resting.
I listened to her and began to apply this principle of resting, every day.
While I was busy learning to apply this principle of resting into my life, my husband decided to help me with this endeavor, by gifting me with a very tiny baby raccoon, who didn't even have his eyes open.
My reaction to this small gift was to tell him, "you take that right back to where you found it"!!! And yes with 3 exclamation points.
So, what did he do, he set up a bed in one of our dog crates, put the recipe for the formula on top of the crate, and then set crate with the raccoon inside it, beside the bed, and left very quickly.
This was a beginning for me. Of course, I did not let that little baby starve to death. What happened was this, after he ate, I ate and when he rested, I rested and when I attended a CPA meeting he also attended a CPA meeting.
This went on for quite a while. That little baby taught me so much about being kind and gentle to myself, that I'm still amazed by it. You know what they say, "When the student is ready the teacher will appear".
My teachers were a baby raccoon, and Chronic Pain Anonymous. I've also learned that life isn't all about me and getting the focus off myself is an invaluable tool that has been given to me.

What I'm able to focus on today, is about being here in Second Life speaking to all of you. Which by the way, I am relatively new to Second Life and I'm fascinated and impressed by this new world.
I fall down a lot while trying to navigate and that is ok, because I've been granted a second life.
One of the activities that I used to enjoy before chronic pain was dancing and the other day after the CPA meeting, a friend took to me a place here in Second Life, where there was dancing.
So, what I have not been able to do in real life, I can do in Second Life, and that is awesome!
And I believe I'm going to end here, thank you everyone for allowing me to share today.

[11:22 AM] KriJon Resident: Thank you Teejens for sharing with us today. I'd like to introduce our next panelist, Ivy Lane (Lee Ann B.).
Ivy Lane was born in January of 2007, while her alter ego Lee Ann B. was attending the University of Massachusetts, Dartmouth. She was created as part of her senior project which needed to be a three dimensional environment.
So Ivy was born a Project Manager destined to create the Turtle Gallery, the first ever online virtual 3D resume used to showcase her artistic abilities and range. She is a successful artist, published writer and a loving mentor.
Chronic pain has been her constant companion for over 25 years now so life is a one day at a time adventure in learning how to cope and still function enough to feel like a contributing member of society.

She spent five years volunteering for a local no kill shelter called Attleboro Friends of Cats, Inc.
This was a life-changing event that brought her into the world of photography and as the Assistant Director of all things Internet she improved their web presence, photographed all kitties and increased adoptions by 66% within the first year of taking the non-profit organization online.
Ivy Lane (Lee Ann B.) will be providing voice and the transcriptionists from VAI will provide her text. Thank you Lee Ann for your service today. The mic is yours.

[11:24 AM] Ivy Lane: ty Shyla
[11:24 AM] Carolyn Carillon: IL: Hello I am Ivy Lane and I live one day at a time with chronic pain.
This is turning out to be an emotional meeting for me
First I have a poem I wrote that I would like to share with you. This poem was written with hopes that I could make others have a brief moment of "feeling" what it is like to live with chronic pain for me.
It's titled Chronic and I wrote this in December of 2011 for my weekly writing group.
Every step is a moment of agony
ankles balk and crack
a teetering gait sways
on points of pain
calves are lost
as shin splints rage
into knees grinding
bone on bone shredding
meniscus into oblivion
thighs once shapely
now juggle and rise into
rounded buttocks
home of the hips smashing
angry nerves in tailbone and
groin, that shoot back to the feet
and up once more waist cinched
for support lungs breath in air
forcing muscles and bones
to sing out their own complaints
that just continue to rise on up
shoulders burdened with life
love and the pursuit of happiness
beg to not be touched even by soft
clothing
and hugs are
a joyful
agony
neck creaks and causes head to hang down
the weight of it all more than one mind

can bear
dark circles under dark blue
eyes display the depths of
madness within
those still pools
one spark of light
still glimmering hope
insane with the desire for mercy.

[11:26 AM] Carolyn Carillon: IL: I have been in a few other twelve step programs.
Sober and straight for over 30 years now, it's been a very exciting and interesting journey.
I have attended AA, NA, OA, and Al Anon. I have found these groups an excellent place to meet people, be supported, network and find positive coping solutions.
I have also suffered with chronic pain due to fibromyalgia for at least 25 of those years as well and thought I knew how to cope with anything!
I was very excited the first time Shyla invited me to Chronic Pain Anonymous.
Since I was in a dark place in my life, having been diagnosed with atrial fibrillation and then unable to walk after multiple hospitalizations
I was quite frustrated and knew I needed to find acceptance as well as to find some new coping solutions for my situation.

At my very first meeting I was able to speak about my situation and listen to others who were already finding ways to cope with varying degrees of daily pain. Having been diagnosed with AFib on top of my chronic pain felt like a death sentence.
In my mind I knew that acceptance is the key to some relief emotionally and spiritually, and to be honest I am still struggling a bit with that first step.
I don't want to accept that this is how my life will be forever, that spending many days feeling like my heart is going to explode in my chest on top of the pain is really not what I planned for when I dreamed at a young age about my life.
I know that acceptance is the only path that can help me change my attitude.
I want to continue to be a mentor, a photographer, a friend, a sister and support to my brother and be a wife to Phil. I want to feel like I am living one day at a time, not dying at any moment.

These are two very different approaches to life. Right now I am struggling with the attitude that I am just living to die. Instead I want to live in the moment and be present and alive now, instead of in fear all the time.
Fear is not the absence of faith, it is instead faith that something bad will happen. I would rather believe that something good just might happen, today, now, right now...so I am working on acceptance so that I can live in the moment.
I don't always appreciate changes, and this one I am struggling with. My counselor of twenty years decided to retire and truly I don't hold that against her or blame her one bit. She has struggled in her own life with a disability and chronic illness.
She has been my counselor, an inspiration and a friend to me.

It is very hard to let her go, I have struggled to think positively about this change in my life and think that my new counselor just might be the support change I need in my life right now to adopt some new coping strategies.

Staying positive in chronic pain is a daily exercise in acceptance, patience and self-kindness. Being at CPA meetings listening to others and sharing is becoming a large part of my support network.
I try to be my own best friend, sometimes it's difficult to detach from the pain that is inside of me and find the parts of me that are loving and thoughtful, it's easier to find them for others, than it is for myself.
That is why going to CPA meetings helps, because I can find others going through the similar situations and share our strength, hope, and experience to cope one day at a time.
I don't know what else to say except that the support of others in CPA, relating to others like myself and going through similar stuff in their life gives me hope.
To identify with others and not compare myself to them seems to lessen the power of loneliness and depression.
Today because of CPA I have hope, not of a cure for the pain, but that I can live with it one day at a time.
That's it for me
Thanks

[11:31 AM] KriJon Resident: Thank you Lee Ann for sharing with us today. Our next panelist is WCD1002 (David S.)
David is a quirky, free thinking, problem solver with a range of interests, from cooking, reading and gaming. In his professional life David is a Public Accountant and Trustee for a charity.
David has a very rare degenerative muscle condition, post transplant 13 years. He has a range of background pain and sudden flare ups.
He suffers with fatigue and is a wheelchair user. David found CPA through the fellowship and is also a member of another Twelve Step Program.
David will be presenting in voice and would appreciate transcription support. Thank you. David, the mic is yours.

[11:33 AM] LV (lorivonne.lustre): DS = David / WCD1002

[11:33 AM] LV (lorivonne.lustre): DS: hello. I am a member of CPA
thank you for allowing me to share my experience with you
I was diagnosed as a little boy, but the diagnosis changed over the years
I am unable to use my wheelchair today, and have been resting from a shoulder flareup so I could be here today
Following my heart transplant I joined CPA and started working the steps so I could accept and appreciate the gift of the heart transplant
I am so grateful for CPA and the fellowship. they are there for me even when I have difficulty with acceptance
especially as my condition fluxes and changes

Acceptance seems so final. I am working towards it.
In CPA I have found others who have the same experiences, and I have a place to discuss my fear without shame
It is hard
On days like this when I am stuck in bed I am reminded of all the times when I was in hospital
I hope to learn to be grateful for what I have – acceptance and release of control to a higher power
I hope to learn to be happy with how I am, to find grace and acceptance
to work with acceptance at a day at a time
I will leave it there. Thank you all and God bless

[11:39 AM] KriJon Resident: Thank you David for sharing with us today. I'd like to take an opportunity to share. So, I am Shyla, a member of CPA. This is my share.
Before coming to CPA, I was very active; some might say an adrenaline junky. I traveled, storm chased, built trails in National Parks, went spelunking and was a writer and performer of stand up and sketch comedy.
I have lived with pain for some time, but always at a level I could 'push' through. Experiencing life was worth the pain to me.
I was in a mode of experiencing life and all it had to offer and didn't think anything could get in the way of that. It was a good time in my life.

However, about five years ago, after surgery to repair a back herniation and confirmation that my early onset osteoarthritis was now bone-on-bone, I experienced a level of pain which woke me up throughout the night, caused insomnia, made it difficult to focus
It appeared to be stealing my life.
Doctors were telling me there was no cure for my situation, but I could not really get my head around that idea. I felt there had to be a cure and a way to get 'my life' back.
I spent a year or more in this effort, spending thousands of dollars and being rather susceptible to quackery.
If a doctor said there was nothing they or anyone else could do for me, I grumbled at their incompetence, fired them and moved on.
I began to talk of nothing other than my pain, which, I understand now, pushed many of my friends further and further away – even family, even the person I wanted as my partner through life.
I was familiar with the Twelve Steps, because I used them daily for another issue. But that Fellowship was not about pain or illness.
The members of that Fellowship could not identify with my experience and I couldn't stop obsessing about it or just 'put it down'. There was no option of abstinence for me.

I then tried various support groups. None felt comfortable to me. None seemed to be helping me move forward in my life despite my pain.
After speaking with another 12-Stepper who also had health issues, I began to search for a Twelve Step group and found CPA.

By this time, I had not just alienated friends and family, my job was at risk. I was afraid I could never find a new position in my current physical condition. Fears of financial insecurity hit me hard. I was good at my work, excellent even.
I could not imagine it would all come to an end. That what I had worked so hard toward might be over. I kept pushing my body as much as I could and I began to cry a lot, every day.

At my first CPA meeting, which was via telephone, CPA'ers took my phone number and after the meeting, they reached out to me.
When they called, I would break down in tears and just bawl. And they, well, they listened and told me it was okay, I was okay, my feelings were okay.
After quite a bit of tears, I began to be able to talk about my feelings, my fears. They would listen, and sometimes they would share things that worked for them.
They might say, "What can you do right now?" And I would tell them how I couldn't possibly get all I needed to get done right now.
They would reassure me it was okay, was there "one" thing I could get done right now? Or even a part of one thing?
Early on I read something out of one of their books I downloaded to my laptop's electronic reader ap. It was from their book, "Stories of Hope".
It was a list of things that CPA member had learned from CPA. I remember crying different tears after reading it. Tears of relief.
I typed it up and added a beautiful background and posted it on my cubicle wall. I posted it at home in my bathroom. I folded it and put it in my glove box.
And whenever something would happen, or someone would say something, that would give me that feeling that my life was over, or I couldn't do this, or whatever, I would read it.

I'd like to share that reading as I posted it in my cubicle. "Things I Learned About Pain" from Stories of Hope.
There's a quote above the reading:
"The fishermen know that the sea is dangerous and the storm terrible, but they have never found these dangers sufficient reason for remaining ashore." —Vincent Van Gogh
It reminds me life isn't always easy, but we live it anyway. Then I put the list of things CPA taught this member.

1. Being in pain is not the worst thing in the world, but being in pain—and all alone—is the worst thing in the world for me.
2. I don't have to feel guilty about having chronic pain. I didn't ask for it. And if I had the opportunity, I would certainly get rid of it.
3. I don't have to feel less of a person if I ask for help. All of us are on this planet so we can support one another.
4. The reason I have chronic pain is not because I am being punished. It is just another intricate part of existence.
People are suffering all over this planet, and I could be in a lot worse state of being than I am.

5. I have always sought out adventures, and with all adventures come risk and hardship. This is just one more adventure I am having, and it, too, shall pass.
6. Pain has led me to be more caring and less egotistical. I have grown to appreciate the really important things in life, like relationships and experiencing moments in the present, as they are happening.
I can now move into the remainder of my life with grace and dignity and peace.
7. And last, but not least, if I am having a bad day and don't want to get out of bed, I don't have to. Neither do I have to feel guilty about not doing anything that day.
The world will not fall apart. Whatever needed attention will still need attention the next day, and the day after that. Maintenance is forever, so there's no rush to get it done.
Thank you for letting me share these thoughts with you today. Our next panelist is TammyzHere (Tammy W.)

Tammy was a poor, single mom while putting herself through university. After graduating, she had some office jobs and ended up in the Chicago building trades.
The job had a 100 lb lifting requirement. She was the 7th woman in her union of 1500 men.
She was collecting unemployment in 2008 when the economy fell apart. During that time, she took care of her mom who died of cancer in spring of 2009.
Two months later, her dad got diagnosed with cancer and had a very debilitating stroke.
She became his full time caregiver.
A combination of things (stress and lack of proper health care) led to Tammy becoming seriously ill with multiple autoimmune disorders.
A series of medical treatments made her medical situation much worse. After being laid up for about 3 or 4 years, Tammy found CPA.
Tammy will be sharing in voice today and would appreciate transcription support.
Tammy, the mic is yours.

[11:48 AM] Carolyn Carillon: TH = TammyzHere

[11:48 AM] Carolyn Carillon: TH: Thank you
My name is Tammy
I'm a member of CPA in Chicago
What my bio failed to mention is that my dad died 6 months after my mom
That's when I was diagnosed
I thought it was stress
I ignored it because I was in good health up to then
I figured it would pass
I started having pain that woke me up at night
I got meds that made me worse
that was in 2009
I was diagnosed with Graves Disease
I was told I'd be better
within 6 months
so I'm counting the months
But I didn't get better

I went back to the doctor
I started trying supplements and diets
I paid thousands of dollars ...
I had a couple of friends
I was having a difficult time with being disabled
I couldn't work
or participate at church
I couldn't attend social functions
I couldn't keep up with the housework
I couldn't function
It took me months to realize I was disabled
Then I found CPA
in SL
I attended the meetings & met Shyla
We talked on the phone
It helped me feel that I wasn't alone
I was obsessed with talking about my symptoms
I was drowning emotionally
I was prematurely old
http://www.chronicpainanonymous.org
I was so weak
It was terrifying
I talked about dying
The people who loved me were having difficulty hearing this
A friend told me she loved me but she couldn't hear this anymore
I felt alienated from people
I couldn't get out & do things in the world
My friends were talking about jobs and dating
I was terrified that I wasn't able to provide for my kids
When I found CPA
I learned to calm down
Being surrounded by other people like me was comforting
I was soothed
that we had common struggles
I wasn't alone
Someone understood me
so I didn't need the people in my life understand this
It made me more emotionally available to them
Instead of being angry at them for not helping me
It was so draining
I couldn't attend to things in my life
As the emotional distress began to subside
I could focus on simple pleasures
instead of loss
There's a grieving process when life changes so dramatically
I found a new normal in CPA

I'm done

[11:57 AM] KriJon Resident: Thank you Tammy. Before we open to questions, I'd like to let you know behind me are several boards with more information about CPA. Please feel free to click them and take the notecards they provide.
You can also visit www.chronicpainanonymous.org for more information or reach out to any of us here, including myself.
At this point, we would like to open it up to questions. You may direct a question to anyone on the panel or it can be a general question which anyone on the panel may choose to answer.

[11:58 AM] Gentle Heron: QUESTION- David spoke about "acceptance." How does this concept relate to trying to avoid shame?
[11:59 AM] Carolyn Carillon: SSG: I'll start and someone might want to jump in
I don't recall in a 12 step program
encountering the concept of shame
I'm just a member
so this is just me
with my understanding
I have felt sometimes
I don't know if it's right
I had a strong expectation of myself to do more
I felt at times
when I didn't rise to the occasion
I felt I should have
What acceptance gave me
is that it got me in touch with reality
My body is in pain
Doing things as if my body isn't in pain
It doesn't help me
It isn't good for anyone around me
So if I accept reality, I don't have to feel bad about what my body's capabilities are today
Does anyone else want to make a statement?

[12:01 PM] Carolyn Carillon: TH: Can you hear me?
[12:01 PM] Carolyn Carillon: SSG: yes
[12:01 PM] Carolyn Carillon: TH: Shame is feeling bad for who I am
I don't have to feel bad today
It's enough to just be me
If someone is telling me that my being is not ok
that's their issue
I just do what I can
I'm gentle with myself
That's important for acceptance
Who I am is enough
That's enough

[12:02 PM] Mook (mook.wheeler): COMMENT: I was quite stunned to hear how Tee and Ivy have so many of the same diagnoses as my husband. My husband has a spinal injury (from an industrial accident) dating back 35 years, and he has chronic pain. But over the years, other conditions developed, including modic 2 changes in the disks, spondylosis in the neck, degenerative disk disease & atrophy, fibromyalgia, osteoarthritis and peripheral neuropathy. I wonder what is the common link in developing these later conditions (seems autoimmune system related). In addition, he has much of what Ivy describes in her poem, from bone-on-bone knee joints, torn rotator cuffs and damaged cruciate ligaments. He is in severe pain 24/7. I try to keep him as comfortable as I can, of course, but he says that what helps him the most is the connection, the communication, and the understanding, with people (me) who care. He said to be able to describe the details of the pain to someone who would listen, not out of duty but because they wanted to, was important.
[12:02 PM] Mook (mook.wheeler): Because pain is largely invisible, people cannot relate to the severity, and cannot empathise. So between us, we devised a scale, for me to understand. The public and medics very often make him feel like he is a fraud. I wish all of you the very best – please continue to reach out to us at VAI. We will be here for you.

[12:04 PM] Gentle Heron: QUESTION- Ivy talked about identifying with others but not comparing yourself to them. Does anyone else want to speak to this concept?
[12:05 PM] LV (lorivonne.lustre): TJ: I can speak on that
When I first started going to CPA I found that people did not talk specifically about their disorders.
All of us have a common bond of being in chronic pain and chronic illness
We have similar emotional reactions
[12:06 PM] Gentle Heron: Right Teejens. Actually our first speaker today was surprised to learn this from working with a cross disability group of bloggers. (She is currently able bodied.) She was surprised by the bond BETWEEN people with different diagnoses.
[12:06 PM] LV (lorivonne.lustre): TJ: Taking the comparing out of it - my pain is worse than yours - makes it so that we can connect
yes Gentle, there are common factors that bind us all together
[12:07 PM] Carolyn Carillon: TH: We don't focus on the differences
It doesn't matter about our diagnosis
It's our feelings about our diagnosis
Fear, depression ...
That's how we're able to unite
By focusing on our feelings rather than the specifics

[12:07 PM] Ivy Lane: May I say something on this
[12:07 PM] Shyla the Super Gecko (krijon): Yes, please Ivy, after Tammy, share
[12:08 PM] Carolyn Carillon: IL: Once I had a sponsor who talked about ...
You don't want to be like nudists
going around looking at each other
Saying I'm so different

You want to go around saying
Oh, I do have two legs or one arm and that other person smiles
It's not about a physical comparison
It's about meeting a person on a spiritual and emotional platform
where we're all equal
because we all have feelings, thoughts & bodies
and that's what we have in common
If we focus on that
We feel
We function
We dysfunction
Everyone feels that
You focus on that point of connection

[12:09 PM] Carolyn Carillon: TH: We focus on the solution rather than the problem
We're helping each other get through life
How to be ok
Not what's wrong
But what's ok today

[12:07 PM] Viv013: When you meet bad docs you just have to keep looking. I've lost track on how many docs I've seen - around 200?
[12:10 PM] Carolyn Carillon: SSG: I've probably seen a dozen doctors who said there wasn't a fix
I had an obsession with going to doctors
In CPA we don't talk about the medical conditions
It's more about the emotional or spiritual condition
If we can focus on that, we can make better decisions
When I finally understood my situation
My focus changed to the quality of my care
To continue my life in this body
With what's available today
As for hope, I leave the door open
I believe in miracles
I'll date them when they come
I believe there's progress
My situation today may be different tomorrow
but I want to focus on enjoying my life today

[12:11 PM] Ivy Lane: I actually really liked what Teejens said, that it was a racoon baby that taught her, sometimes it doesn't even take a human to help us, it takes identifying with a being .... to learn to be better at being ....

[12:12 PM] Leandra Kohnke: I have a family member with chronic pain and he was initially diagnosed as psychosomatic and he was sent to a psychiatrist. Now seeing the psychiatrist has helped in many many ways and he is a much nicer, easier to be

around, person, more content. But it did nothing whatsoever for his chronic pain. (Which turned out to not be psychosomatic.) He still has that. Do you think CPA helps in that way as well?
[12:13 PM] Carolyn Carillon: SSG: I think my doctors do
As I came to acceptance, I changed the way I interacted with doctors
Because I'm in pain doesn't mean I have to be a pain
from a CPA perspective, we don't get into the medical issues
If someone tells me they're in pain personally, I believe them
That was one of the issues I had at work
That was quite challenging
This is where CPA helped me calm myself
So I could start sorting out the process that we go through

[12:14 PM] Gentle Heron: Thank you all so much for sharing with us today. Several folks are mentioning how moving this all is. I think it's important to understand that we have many more similarities that can bond us than we have differences.

[12:14 PM] Gloriejoy (joycie.string): thank you all so much
[12:14 PM] Gloriejoy (joycie.string): one learns more when sharing
[12:14 PM] KriJon Resident: Thank you for coming today.
[12:15 PM] Carolyn Carillon: SSG: thank you Gentle & VAI for inviting us
[12:15 PM] Svea Morane: Thanks very much for your bravery and confidence in sharing with us.

[12:15 PM] LV (lorivonne.lustre): <transcription ends>