

# 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](http://maps.secondlife.com/secondlife/Virtual_Ability/54/170/23)



Speaker: Caroline Pavis

Title: "Engaging and Empowering Online Health Communities"

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[07:56 AM] LV (lorivonne.lustre): Hello everyone.

Today's 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.

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Speaker: Caroline Pavis

Title: "Engaging and Empowering Online Health Communities"

The transcriptionists are:

LoriVonne Lustre

Carolyn Carillon

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

CP = Caroline Pavis

[08:00 AM] Gentle Heron: Good morning everyone and welcome to the Virtual Ability community's 2016 International Disability Rights Affirmation Conference, also known as IDRAC. I am Alice Krueger, and I'm proud to be president of Virtual Ability, Inc., the nonprofit which supports the Virtual Ability community in virtual worlds.

You will meet many community members today. Some are presenters, others greet those attending as they arrive at the auditorium.

Still others have the honor of introducing our esteemed presenters for each session.

Many others help behind the scenes.

IDRAC is an opportunity for our community to celebrate the rights we have and continue to strive for as persons with a wide variety of disabling conditions and chronic health issues.

The theme of our 2016 IDRAC conference is "We're part of the community."

The presentations today and tomorrow interpret that theme uniquely.

Some presenters will explain the need persons with disabilities have for being part of a community, and the value to the community of including them.

Others will talk about various aspects of community living: access to healthcare, use of technology, responses to emergencies

Still others will talk about how persons with disabilities use various types of technology, including social media and virtual worlds, to participate in community activities.

We hope our audience will come away from this conference with a better understanding of the importance and significance of increasing the concept of diversity to include persons with disabilities as well as other minority groups.

After all, being disabled means you are in the largest minority group of all!

Before we begin, a few housekeeping reminders:

1. If you have trouble hearing voice or seeing the slides, please IM the greeters who are standing at the back of the auditorium at the top the aisles. They will be happy to assist you.

2. To be as fully accessible as possible, we will do all presentations in voice+text. Some presenters will use a text teleprompter when they speak. Others will rely on our transcribers to type what they say.

To allow our Deaf audience members to follow the flow of the presentation, we ask that everyone please hold your comments and questions until the end of the presentation.

You may want to open a notecard and type your thoughts there to save for the Q&A portion of the presentation.

3. Please click the “Welcome to Virtual Ability Island” poster up front here to get information about our schedule and exhibits for today and tomorrow.

Please pick up a commemorative T shirt outside the auditorium.

Now please welcome Amvans, who will introduce our first presenter.

[08:04 AM] amvans Lapis: Good Morning! My name is amvans lapis in Second Life and Marie Vans in first life.

I am a research scientist at HP Labs in Fort Collins, Colorado, where I work on document understanding and imaging technologies.

It is my pleasure to introduce our first speaker, Caroline Pavis.

She currently serves as Communications Leader for Janssen Biotech, Inc., a division of Johnson & Johnson, where she oversees integrated public relations and communications initiatives for Janssen’s Oncology and Immunology Business Units.

Caroline joined Johnson & Johnson in 2011. Prior to joining Janssen Biotech, Caroline served as Director, Global Communications for Johnson & Johnson Diabetes Care.

There she led internal and external communications on behalf of the global franchise and served as a member of the Animas Management Board.

With nearly 20 years of public relations and corporate communications experience, Caroline joined Johnson & Johnson from GolinHarris.

GolinHarris is a global public relations consultancy agency, where she was responsible for overseeing strategic marketing programs for several pharmaceutical, medical device and consumer healthcare companies.

Caroline lives in Coopersburg, Pa. with her husband and three kids, where she is adjusting to the quiet country life (and endless yard work) after moving from the big city of Chicago.

Please welcome Caroline.

[08:05 AM] LV (lorivonne.lustre): <transcription begins>

[08:05 AM] LV (lorivonne.lustre): CP = Caroline Pavis

[08:06 AM] LV (lorivonne.lustre): CP: Good morning. Can you hear me?

What a pleasure to be here. Thank you to Gentle for the opportunity and patience.

(Slide 1) Here I am talking at our HealtheVoices conference.

I work in PR, but what I really do is reach out to the community and work with patient advocates.

HealtheVoices is something I am very proud of. We are looking to extend this beyond an annual conference. I think I will learn a lot from you here today.

Slide 3. What is an “online patient advocate”?

This is someone who is helping others who are living with a chronic health condition. Many do this in addition to their day jobs. Some have health conditions themselves.

This slide shows how we tap into social medias to connect with communities - Twitter, Facebook, blogs, vlogs,

Many of you probably fit this description as well.

#### Slide 4. Realities of Health Advocacy

I work with people who have many chronic health conditions, particularly in oncology.

I noticed that there were not a lot of gatherings for health advocates -- there is little funding and support for this group and most do this in their spare time.

Many are unable to take classes or find other ways to connect with one another.

#### Slide 5. Advocates Need Support

Online health advocates are hungry for support and networking opportunities that will allow them to learn and better serve the people who turn to them for support.

Online health advocates needed support to connect with one another.

#### Slide 6. Janssen's Unique Opportunity

Janssen organized HealthVoices in order to provide resources, facilitate connections, further strengthen relationships within and across patient communities, and foster excellence in online health advocacy.

Janssen saw this as a unique opportunity to find ways to support these individuals, regardless of the health condition.

Someone working with an HIV community could connect with another working with mental health advocacy -- learn from each other.

Just as all of you work and learn together.

HealthVoices 2015 was the first conference and we learned a lot!

HealthVoices 2016 grew from 50 participants to 90

<http://www.healthvoices.com>

Janssen issues a call for applications in January. Check Twitter as well.

I would like to show you a video now.

[08:18 AM] Gentle Heron: To view the video, please enable media (in Preferences or using the speaker icon at the top right of your screen) and click on the video screen up front showing the HealthEVoices logo.

If you prefer to watch in your own browser, please click here: <https://vimeo.com/180357038>

[08:18 AM] LV (lorivonne.lustre): Please click on the video link.

There is a transcript in the giver box at Caroline's feet up front.

[08:22 AM] CarolinePavis: Please let me know once you have had a chance to watch the video  
[08:22 AM] iSkye Silverweb: Hopefully some of us can say "back" or "here" when done viewing the video  
[08:23 AM] Marie (amvans.lapis): back  
[08:23 AM] Leandra Kohnke: back  
[08:23 AM] iSkye Silverweb: back  
[08:23 AM] Shyla the Super Gecko (krijon): back  
[08:23 AM] Mook (mook.wheeler): back

[08:23 AM] LV (lorivonne.lustre): CP: thank you for taking the time to watch the video.  
It gives a glimpse into what we have done, and we are very much interested in extending this throughout the year via social media  
Our focus is to reach as many health conditions as we can  
As you can see from this chart, we would really like to have a more diverse audience in 2017.  
In 2016 we welcomed global participants and would like to expand this as well.  
We could not even guess what kinds of topics and sessions people would be interested in.  
We have an amazing advocacy advisory panel  
Panelists represent many different health conditions.

Slide 11. Focus on empowering advocates with educational tools & resources  
Here you see some of the topics from 2016 – how to create blogs, how to deal with legal issues  
Copyright  
We had a lawyer who is an expert in social media to help participants learn how to manage their content and control IP.  
We had another session on keeping your content fresh.  
And how to look at the metrics of who is looking and using your content.

Slide 12. Breakout Session Leaders  
Here are some of the expert presenters from 2016.  
We are looking for presenters for 2017.  
Another great topic was helper fatigue – how to take care of yourself!  
Those are some samples. We offer 2 tracks  
2 concurrent sessions

Slide 13. Keynote Speakers Energized the Crowd  
These are keynote speakers from 2015 and 2016.  
One spoke about the disconnect between docs and patients.  
He has created fun videos to educate patients.  
Patients Like Me - Jamie Hayward was another great speaker.

Slide 14. Promoted virtual participation

We want to make the conference more virtual -- and why I am so happy to be here with you today.

From our Twitter handle we shared sessions

But I think we can do a better job

We had a graphic artist creating representations of each session.

We had a great response on social media -- and was even trending on Twitter!

We had a great recap of the conference on social media as participants share what they learned with their communities.

Slide 17. Forging long-term relationships

Attendees have created a bond that lasts.

Slide 18. 2016 Attendee Feedback Survey Results

Slide 19. 100% of Survey Respondents rated their Experience as "Very Good" or "Excellent"

This word cloud shows the 1 word responses that attendees shared.

HealtheVoices 2017

Return to the Windy City

When & Where?

April 21-23, 2017

Chicago is a better alternative for most attendees.

Slide 23. Expand Live Virtual Participation

Continue utilizing @HealtheVoices

Twitter handle to share live updates, plus:

Create public HealtheVoices Facebook Group to share similar updates as Twitter handle

Stream select content to remote audiences using livestream (Facebook) and Periscope (Twitter)

We want to expand the virtual participation.

I know I can learn a lot from you here.

Thank you. Do you have any questions or suggestions for us?

[08:39 AM] Gentle Heron: QUESTION- I know you are new to virtual worlds. Once you are more familiar with Second Life, might you consider helping set up a blogger round table here in the virtual world? Or some other type of online/virtual world support?

[08:39 AM] Carolyn Carillon: CP: I'd love it

100 times YES!

I would love to do that! 100 x YES!

We're depending on people here

The more we can do to reach people who need support  
It makes me happy

[08:40 AM] Leandra Kohnke: I have done scientific conferences where we had both SL and in person going at the same time. People in SL presented in RL and watched RL presentations in SL. The immersive environment of SL combines very well with RL.

Not to mention VWBPE!

We had presenters from China, Russia and Europe at our conference while we were in physically in Toronto. Works marvelously well.

[08:40 AM] iSkye Silverweb: Mixed reality experiences - they are really awesome

[08:41 AM] Pianoman (p1an0man): Yeah, we had one of those with the Dalai Lama... was really cool.

They had an avatar and everything.

[08:41 AM] Shyla the Super Gecko (krijon): Have you considered those who cannot attend - I saw very few with back issues in your slides - mostly because conferences are difficult for us...but what about allowing us to attend through a computer terminal using whatever virtual environment works for us? The laptops would not be too expensive, and perhaps after could be donated back to members of our community desperate for them who cannot afford them?

[08:42 AM] Carolyn Carillon: CP: Very interesting

I'd love to get your advice to make that happen ... a mixed reality conference

I'd be open to any of those suggestions

I would love a recommendation

About what would be better

A virtual reality conference?

We did have people in wheelchairs

And people with chronic pain

etc

And we can always do better

But what we tried to do

Is bring in comfortable & reclining chairs

We also had a relaxation room

If anyone is not feeling well

They can go sit in a quiet room with music and heating pads

To relax until they can return

I think we can always do more

I'm open to suggestions

[08:42 AM] Leandra Kohnke: Combine both to get the best of both.

[08:43 AM] iSkye Silverweb: Livestreaming the inworld conference to the web - this is useful for those who cannot get into SL or due to some technical issues cannot get to the virtual venue, they can still see it livestreamed.

[08:43 AM] Carolyn Carillon: CP: Do you know the name of the conference (with the Dalai Lama)?

[08:44 AM] Carolyn Carillon: Gentle will email CP

[08:44 AM] Carolyn Carillon: CP: these are all great ideas ... thanks!

[08:44 AM] Gentle Heron: QUESTION- One of your speakers in the video said it was hard to connect in a virtual world. I disagree. How can we explain to them the level of connection we feel in this community here? What do they need to hear?

[08:45 AM] Shyla the Super Gecko (krijon): Gentle, I agree, Twitter, Facebook and others are considered "Virtual" to them...

Second Life would blow their minds!!!!

[08:45 AM] Carolyn Carillon: CP: I think they need to experience it

This is an idea I have for the conference

There could be a session to learn about virtual reality

When people talk about the connections at the conference

Many have talked over email, etc

But they've never met in person

So meeting someone in real life can be powerful

But maybe they could use a technology like this

And feel connected in a special way

I wonder if we should do a session on virtual communities

To educate advocates about this place here

[08:46 AM] Shyla the Super Gecko (krijon): Yes, please consider that!

[08:46 AM] iSkye Silverweb: Virtual worlds like SL are environments where the 'sense of presence' is very strong and very immersive

We can be sitting in different parts of the world and yet feel like we are next to each other

[08:46 AM] Gentle Heron: QUESTION- Caroline do you feel you are "with" your audience now?

[08:46 AM] Carolyn Carillon: CP: I do feel like I'm with you

I really do!

It's interesting watching the comments coming through

That's fantastic

I'm anxious to do more myself in SL

[08:47 AM] iSkye Silverweb: That's the sense of presence when you are 'here' with us

[08:47 AM] LV (lorivonne.lustre): I also work on a 24 hour virtual conference via Adobe Connect - Virtual International Day of the Midwife



VIDM: <https://vidofmid.wordpress.com/> 05 May 2017

[08:47 AM] Shyla the Super Gecko (krijon): There are also drawbacks to virtual worlds, so it is important to share those too - technology barriers, computer requirements, motion sickness, particle effects - most can be overcome, but it would be good to address them and be reassuring about it if discussed at a conference...

[08:49 AM] Leandra Kohnke: You do need the right support people who are knowledgeable.

[08:49 AM] iSkye Silverweb: That's why we have mentors available

[08:49 AM] Gloriejoy (joycie.string): I have my clients to our home and have varied comfort furniture for all comfort needs to feel comfortable. I had an ADA ramp installed in our garage to keep everyone out of inclement weather! I have an office for specific learning needs as I show and demonstrate varied computer sessions for them individually e.g. how to start their own accounts, listening/viewing to virtual sessions, etc.

[08:49 AM] Carolyn Carillon: CP: that's really impressive

[08:50 AM] Shyla the Super Gecko (krijon): If you put Ergoquest chairs at the conference, I might be able to attend this year - you are only 40 minutes from my home, but I can't sit or stand more than 10 mins or so...but I wish I could go!

[08:50 AM] Carolyn Carillon: CP: I would love to have you

[08:50 AM] Gentle Heron: Folks can we tell Caroline where we are from?

[08:50 AM] LV (lorivonne.lustre): Nova Scotia. Canada

[08:50 AM] Pianoman (p1an0man): Louisville, KY here

[08:50 AM] Gentle Heron: Tennessee US

[08:50 AM] iSkye Silverweb: near Green Bay, Wisconsin

[08:50 AM] Leandra Kohnke: Alonsa (a small village near Riding Mountain National Park.)  
Manitoba Canada

[08:50 AM] Zip Zlatkis: Virginia

[08:50 AM] Ruby Vandyke: Vancouver BC

[08:50 AM] Mook (mook.wheeler): currently living in Liverpool, UK

[08:50 AM] Eme Capalini: Austin, Tx

[08:51 AM] Huntress Catteneo: Australia

[08:51 AM] Gloriejoy (joycie.string): I am from Lansing area Michigan

[08:51 AM] Sage (sageclearwick): Los Angeles area, CA

[08:51 AM] LV (lorivonne.lustre): CC is in Nova Scotia too

[08:51 AM] Marie (amvans.lapis): Fort Collins, CO

[08:51 AM] Shyla the Super Gecko (krijon): Chicagoland, IL

[08:51 AM] Gentle Heron: [08:51] Zelda Fromund: Minneapolis, Minnesota

[08:51 AM] iSkye Silverweb: we're from all over the globe but we are all 'here' together

[08:51 AM] Carolyn Carillon: CP: You can really feel that  
It's incredible

I want to thank you all for listening to me

Letting me speak about HealthVoices

I'll continue to hone my skills in SL and learn more!

[08:52 AM] LV (lorivonne.lustre): <transcription ends>

[08:52 AM] Gentle Heron: Thank you so much for presenting and learning about SL.

Thanks to VAI folks who helped this morning.

Please take time between sessions to visit the Displays and Exhibits on Healthinfo Island, to our west.

Displays:

The l'Arche Story <http://maps.secondlife.com/secondlife/Healthinfo%20Island/196/157/23>

The History of the Independent Living Movement

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/190/179/24>

Why is Community Important to People with Disabilities

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/172/154/22>

Exhibits:

Jean Vanier on Disability

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/113/78/24>

What Defines Community?

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/96/41/26>

The Role of Organizations for People with Disabilities

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/51/27/28>

Jean Vanier on Community

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/25/25/30>

What do you call people with disabilities

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/21/63/32>