“Words Matter: You can choose the title of your own story”
Heather Markham, Making Waves for Good
International Disability Rights Affirmation Conference 2023
November 10

[Hello everyone.
Today's presentation is being transcribed so those without audio or who require text only can participate in real time.
Some speakers may be using a text teleprompter tool for some or all of their presentation.
Transcriptionists will fill in any gaps and support the Question & Answer section at the end.
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 local chat.
Transcription is provided by Virtual Ability, Inc.
The transcriptionists are:
Elektra Panthar
Lorivonne Lustre
The speakers will be identified by initials as they speak.
The following initials in the transcription record will identify the speakers:
HM: Heather Markham]

[2023/11/10 13:33] LV (LoriVonne Lustre): Coming up next: Heather Markham, Making Waves for Good
Words Matter: You can choose the title of your own story

[2023/11/10 13:35] Basona Melody: Words are delicious. Words like kismet, serendipity, or lagniappe.
I especially like lagniappe which I learned while living in New Orleans.
It means a happy surprise and describes my opportunity to introduce our next presenter to you.
Heather Markham will be speaking about the power of words in creating your life story.
My own story includes the joy of raising two adoptive black sisters.
I saw too how a single racist word can crush a child's spirit.
Americans who lived through integration saw how a simple phrase like "I have a dream." can inspire a nation.
Heather was diagnosed at age 34 with a progressive muscular dystrophy.
She used the power of words in her own life to become a para-surfer, an adaptive technology professional, an engineer, and an award winning photographer.
Here she is, I introduce Ms. Heather Markham to tell you more in her own words.

Please hold your questions until the end of her presentation. You may use the ampersand to show that your hand is raised to speak at that time.

[2023/11/10 13:38] LV (LoriVonne Lustre): <<transcription begins>>

[2023/11/10 13:37] Elektra Panthar: HM: indeed, words matter
Words are labels, and you can choose the words used for you and about you
Once upon a time - that photo on the left is me when I was 3. I was a bit clumsy and took longer to heal but it didn't arouse suspicions
In college I was less clumsy, but in 1990 I injured myself and it started, my legs wouldn't heal
As my disease progressed I began running into challenges
I wasn't diagnosed until 2002
There are logistical challenges
A transport chair is like a kitchen chair with wheels, can't be maneuvered
Currently I use a power wheelchair, with many options, but still gravel and grass are problematic
Another thing is adaptive elements - duct tape is your friend
Here you can see an event where someone needed to push the chair , or to pick me up, for this surf event
Even a high five is a problem now because of my condition
I'm grateful for my friends and small things that remove some of these frustrations
I put these titles to show you that I'm a restless spirit, I do things because I'm curious, or did some jobs for necessity
It's possible to reinvent yourself
I began to use more technology as my condition progressed

[2023/11/10 13:48] Carolyn Carillon: AFO = ankle foot orthoses
[2023/11/10 13:48] Elektra Panthar: HM: yes, ankle foot orthosis
I needed to use those, and a cane, and other tech, some low tech some high tech
People tend to shorten things "that lady with the cane", or "the lady with the dog"
Tech doesn't make my identity or less than, just because it's with me every day
I know I'm preaching to the choir
My rollator gave me a place to sit, my scooter allowed me to go longer distances
My service dogs freed me from isolation, and my power wheelchair now can also stand me up
Everyone is going to want to pet that dog
SL gives freedom, in RL sometimes tech can be limiting
From this pic the wave looks like it's about to smash Spike into smithereens
Spike's from England
I have to remind you, but life is more like this party wave (everyone's on it)
Some slower, some faster, others doing their own thing, some standing nearby to help,
Others in the background, those are spectators and not your friends, not part of your team
The next morning we went to a beach, I was paired with a young guy. He helped me get on the surfboard and then [we hit] the water

The water conditions made it difficult, I was pummelled at first
[2023/11/10 13:57] LV (LoriVonne Lustre): Notecard with Rough Waters in the giver
[2023/11/10 13:57] Elektra Panthar: HM: I wanted to fly but my board jettisoned itself out as I tumbled in a wipeout
He found me, I clung to him, and wanted him to take me back
He asked if I was sure - I drove 400 ml to get here
He brought me back
“There were some big ones today,” he said. It wasn’t a question. He was a surfer and, although he surfed standing up, he knew that a five-foot wave could feel like it’s twenty feet high when you’re lying down.
Toweled off and back on my manual wheelchair, I was taking photos of various other surfers when I saw my friend Jay being carried out for his set. He lived with tetraplegia as the result of a trampoline accident in high school, and although in his late thirties, he seemed ageless to me with his very, very thin frame and his hair sheared to nearly stubble. While part of the team carried him, others carried his board, which was big and floaty. …
Jay’s board had been custom made for him by Channel Islands Surfboards in California. At the nose was a large sticker that read “Surfgimp”—in flourishy script, with artwork of a person sitting on a manual wheelchair, riding a surfboard—as that was Jay’s title for himself. …
He surfed every weekend, and around his home beach in Delaware, he had a crew of about fifty people that he called “Team Surfgimp.” I focused my camera on him. He caught the first few waves without a problem, but on the last one, he had a massive wipeout. The board went shooting off at a forty-five-degree angle, and he got thrown off. It looked bad from where I sat, as the fifteen in-water volunteers on his [Life Rolls On] LRO team all raced toward him, where he was floating facedown in the water. Jay’s team and family and friends all knew that he didn’t have any muscle control below the level of his spinal cord injury at the C4-C5 junction in his neck, which meant he couldn’t roll himself over. My hips and shoulders were weak, but I could still flop around and rotate enough to get myself righted. The thought of not being able to roll over frightened me. I counted the seconds, afraid he had been knocked unconscious . . . one . . . two . . . three . . . four . . . five . . . His team got to him,
righted him so that he had air, and supported him on the water while we all waited. As I remembered to take in my own breath, I took a photograph that still resonates deeply for me.
Through my long zoom lens I could see his smile, even though his team looked anxious. He was talking to them and reassuring them. I have no doubt that, if his thirty-minute set hadn’t been up, he’d have found a way to convince them to put him back on that board to catch another wave. But for today he was done. They carried him out of the water, put him back on his own manual wheelchair, and then brought him back to where the rest of the surfers were sitting. Once the chaos of the transition had settled down, and his wife had dried him off, I went over and asked him about the wipeout. We had surfed together before, so I knew he would take my question for what it was. Simple curiosity.
“What do you do when you end up like that? Facedown? Isn’t it scary?”
“I hold my breath and wait. I don’t worry. I know they’re coming for me.”
He trusted his team. He had faith in them.

It seems very simple, but this struck me as profound. How often was I in a situation where I should just wait and have faith instead of floundering around and panicking? Reflecting on his attitude, I later came up with a personal motto from a combination of Hebrews 11:1 and The Hitchhiker's Guide to the Galaxy: have faith, don't panic, and always carry a towel.

[2023/11/10 14:03] Carolyn Carillon: HM: I intended to show a video here but decided to use still photos
These are from the go pro camera on my surf board
I was just struggling for balance
I was learning to my right
That's why the horizon doesn't look straight
At my feet was Tony
He helped me choose waves
And kicked like crazy to launch me into them
This is when the swell reached me
The wave is just breaking
Up close it's nearly see-through
The wave has now picked up the board
I finally looked where I was going
You can tell the speed from the side rails
The wave was dying out
I moved to Arizona just before COVID
After restrictions lifted, I looked for things to do
I live in a retirement community with a golf course
That seems natural
I relearned how to swing a golf club
With a wheelchair
I can use the standing feature of my chair
Next I had to find a place to practice
The driving range wasn't accessible
So I advocated for change
I looked for people who had the power to change
Eventually I got a curb cut put in
And a ramp
So I could get on the driving range
The blue stripes stop people from parking their golf carts
I love the sunset
Dads being dads, he rolled his eyes when I told him I was golfing again
Because he couldn't picture it
I invited him to watch
He thought it was ... interesting
And that my shots were consistent
[From Dad] that's high praise
I'm getting stronger and making improvements
My golf instructor is pleased
This is me standing to putt

During an Ability 360 clinic
I made the putt
I had two elastic bands to keep me in contact with the club because my grip is weak
[2023/11/10 14:09] Orange Planer: Question:
Ever get a "Can I play through?"
[2023/11/10 14:09] Carolyn Carillon: HM: I've only played at the clinics
And it's just us
I'm slow
So we let people play through
It comes with the territory

[2023/11/10 14:10] Carolyn Carillon: I've been photographing since I was a teenager
I wanted to see how good I was
I entered contests
This one came in third
The jury doesn't know I'm using a wheelchair
So when I accepted, I got to doubly represent
I'm thrilled they got to see ELITE wheelchair athletes
I get a lot of questions about taking photos when I can't pick up my arms
I have a tiny tiny camera with a large sensor
It doesn't have a screen that tilts so I can't always see everything
I shoot a micro 4 thirds
It tilts and rotates
I love it
I use my wheelchair to tilt to get good angles
I use my phone to trigger the shutter
This photo is called Jailbird
This heron thinks he's hiding from me

I wanted to put the titles back up
So I can talk about how these relate to identity
People associate their job titles with themselves
I'm a photographer
What if I can't take photographs?
What if I can't golf anymore?
With some of these categories I'm actually an advocate
I'll always be a writer whether I author another book or not
Let's consider identity labels and how they relate to attributes
As a photographer, I'm patient
As a surfer, I'm a problem solver
As a golfer, I put up longsuffering
As an advocate, I'm personable, curious, compassionate & tenacious
As a writer I'm wordy
These are really skills
And skills can be learned

I'm going to read another excerpt from my book

About choosing 5 words to describe myself

FROM THE EXCERPT:

There was another round of interviews in the afternoon, and then we were given some time to sit and collect our thoughts before the public part of the pageant began at 3:00 p.m. I sat in a corner of the lobby and scribbled notes on index cards about the “five words” that we used to describe ourselves. We’d had to submit them with our application, and they were printed in the program beside our picture. I would now have to elaborate on them and answer two random questions from the judges, in something like thirty minutes.

Whatever I had managed to write down would have to be enough. I went up to my room, brushed my hair again, and did a makeup and wardrobe check to make sure I looked “finals ready.” We were told not to wear a gown, so I’d chosen a smart pink wool suit jacket with a cream silk blouse and an off-white, fine wool skirt from Talbots. My pageant shoes were silver-glittered, sling-back, peep-toe pumps with a kitten heel. I had been all about the sparkle when I belly danced, and sitting down hadn’t changed that. I was determined that, winner or not, I would shine.

With fifty people in attendance in a small hotel ballroom, we talked about our five words. I was handed the microphone, and I planted my right elbow on the wheelchair’s armrest to steady it. Bending slightly sideways so that I spoke directly into it, I read each of my words aloud—advocate, creative, compassionate, adventurous, and loved—and I elaborated on each one the best that I could, using what I’d written on the note cards while sitting in the lobby, except that I didn’t elaborate on “loved.” It was the card I hadn’t had time to get to, and now words escaped me. My ad-libbing brain froze. So I just let it sit.

I saw people in the room shift in their chairs, and I heard the women behind me on their wheelchairs moving also, so I was sure that last word rankled some people. Maybe it was seen as too bold, too brash, or narcissistic. Everyone is loved. How dare I include it! But I didn’t mean “beloved,” as in everyone thinks I’m amazing. I meant that I knew I was loved by God, and I was also loved and supported by my family and friends. It is their fierce love that holds me up and lets me boldly put myself out there and reach for my most impossible dreams.

These were my words in 2012 or 13

I think my list now would include believing, curious, tenacious, grateful and brave

Making it this far with an unknown prognosis, this is how I move through the world

People say I have a good attitude

It's one of the few things I have control over

Every day we decide who we are

You get to choose the title of your own story

I do this 5 Word Challenge weekly

What are your 5 words?

This is how you find me

Any questions?

[2023/11/10 14:21] LV (LoriVonne Lustre): Contact info in the giver

[2023/11/10 14:21] HeatherCMarkham Resident: YouTube clip: https://youtu.be/yNmvzSm-fyI?t=10204

[2023/11/10 14:21] Faith Frances (Roxie Marten): Question: Have you considered scuba diving, it's when you're disabled
I love negative buoyancy
[2023/11/10 14:22] Carolyn Carillon: HM: I have considered scuba diving
It hasn't made my list yet (laughs)
Jumping out of an airplane is on my "next 3 years" list
[2023/11/10 14:22] Lorin Tone: Great!
[2023/11/10 14:22] Mook Wheeler: Heather -- three more words come immediately to mind with you: "Never give up."
[2023/11/10 14:22] Faith Frances (Roxie Marten): no jumping out of good working planes LOL

[2023/11/10 14:22] Attica Bekkers: Are you still writing?
[2023/11/10 14:22] Carolyn Carillon: HM: I am still writing
My photo website has a blog
www.justforthelove.com
I'm newly engaged to my high school sweetheart and we're going to write our story
[2023/11/10 14:23] Faith Frances (Roxie Marten): awesome
There is love post-disability my partner and I know this
[2023/11/10 14:23] Attica Bekkers: congratulations!!!
[2023/11/10 14:23] Gemma (Gemma Cleanslate): lovely
[2023/11/10 14:23] Lady Tigress Bonded (pet Karu): congrats!
[2023/11/10 14:23] iSkye Silvercloud (iSkye Silverweb): Woot!! Congrats!

[2023/11/10 14:24] Carolyn Carillon: HM: ok, if we're done I'm going to stand up and walk away!
I made it work!
[2023/11/10 14:24] Attica Bekkers: thanks
[2023/11/10 14:24] LV (LoriVonne Lustre): Applause!
[2023/11/10 14:24] Gemma (Gemma Cleanslate): /me APPLAUDS!!!
[2023/11/10 14:24] Elektra Panthar: ♫♪♫♪ Applauds ♪♫♪♫
[2023/11/10 14:24] Lady Kirsten McLeod (KirstenMcLeod Resident): claps her hands with wild enthusiasm
[2023/11/10 14:24] Lorin Tone: Bravo!
[2023/11/10 14:24] iSkye Silvercloud (iSkye Silverweb):
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[2023/11/10 14:24] Buffy Beale: very well done thanks and Bravo!!!
[2023/11/10 14:25] Lady Tigress Bonded (pet Karu): your presentation was very encouraging
[2023/11/10 14:25] Delia Lake: thank you very much, Heather.
[2023/11/10 14:24] Gentle Heron: Great presentation Heather. Thank you

[2023/11/10 14:24] Carolyn Carillon: <<transcription ends>>

[2023/11/10 14:25] Pecos Kidd: Hello again, everyone. Gentle is still having network issues, so I'll do the closing remarks.
Thank you for spending time with us today. We have all learned so much from our presenters.
On behalf of Gentle and all the volunteers who organized this conference, we are grateful to so many people today.
First, thank you, audience, for sharing this conference with us. Without you the conference would not exist.
And of course we want to thank today's presenters.
Our heartfelt thanks to those presenters who were new to Second Life for their courage coming into a new (to them) world for this conference:
Joseph (and his caregiver and James), Erin, Daniel, Emily, John, Mark, Keri, and Heather.
Thanks also to SL veteran Judy for presenting today.
I want to especially thank all the Virtual Ability community members who volunteered and contributed to today's success.
That includes several folks who WERE going to help out, but have come down sick. Thank you for the work you had put into preparation.
Panel moderators Thomas and Itico led fascinating short sessions.
Panel members Carla, Phoenix, Timm, Daisy, Don, and Tarquin shared themselves and their work with us. Thank you all.
Thanks to the Virtual Ability community members who introduced the presenters' sessions: Moose, Attica, Voltek, Andee, Minka, and Basona.
Thanks to Shyla for interviewing Keri and for voicing when needed.
Thanks to Demelza and iSkye for creating the stage setting for our interview segment.
Thanks to Orange for helping resolve the always expected, but still unexpected, technical issues.
Our greeters are the first contact with the Virtual Ability community for many attendees.
Thanks to Gemma Cleanslate for organizing the greeters, and to Adro, Vulcan, Linn, Lorin, Saxon, Sitearm, Sorrell, and Faith for greeting our guests.
Thanks to our behind-the-scenes streaming team: Marcus, Rhiannon and James. Great teamwork, guys.
Very special thanks and icepacks for their RL non-avatar wrists to our loyal transcriptionists: LoriVonne, Carolyn and Elektra. They do such important accessibility work.
Thank you to Mook and iSkye and Eme for their support and hard work throughout the months leading up to today.
And of course, our heartfelt thanks to Gentle. Our whole Virtual Ability community started with her, and is constantly reinvigorated by her.
And she does so much work behind the scenes to make each of these conferences happen that it's just astounding.
We will be archiving the text chat and the videos of individual sessions for future review or if anyone missed a session.
A quick reminder to visit the poster sets on Healthinfo Island (to our west) for additional information about lymphedema and Down syndrome, ableism, family caregiving, and other pertinent topics.

A notecard about this month's Healthinfo Island poster sets is in the blue sign on the left of the stage.
Please stay healthy, everyone. We hope to see you at our next conference in the spring.
Let's continue to enjoy our virtual world together!

[2023/11/10 14:30] Gentle Heron: Thank you Pecos. The best compliment I got today was seeing how well the conference ran without me. We have a wonderful team.
[2023/11/10 14:30] Orange Planer: Yeah, they got you all on tape, and don't you forget it!
[2023/11/10 14:30] iSkye Silvercloud (iSkye Silverweb): Gentle has a magic touch to finding excellent presenters
[2023/11/10 14:30] Buffy Beale: Cheering Loudly! Congratulations to Gentle and the whole team on another most successful conference!! What a wonderful day of learning! Thank you very much and see you next year!
[2023/11/10 14:30] LV (LoriVonne Lustre): The VAI team is awesome!
[2023/11/10 14:31] Delia Lake: This has been a wonderful conference! I came this morning and planned to stay only through the NPC meeting time. I was so captivated by all the presentations that I stayed the entire day and am so very glad I did. I learned a lot and am leaving so inspired! Thank you everyone for this conference. Yay VAI!
[2023/11/10 14:31] Lady Kirsten McLeod (KirstenMcLeod Resident): overwhelming . .. heartwarming!
[2023/11/10 14:31] Elektra Panthar: ♫♪♫♪ Applauds ♪♫♪♫
[2023/11/10 14:31] Orange Planer: And please visit https://blog.virtualability.org and https://www.virtualability.org!
[2023/11/10 14:31] Lady Tigress Bonded (pet Karu):
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[2023/11/10 14:31] Lady Kirsten McLeod (KirstenMcLeod Resident): thank you for allowing me to participate!
[2023/11/10 14:31] Marcus Llewellyn: Woot!
[2023/11/10 14:31] Buffy Beale: Great to see everyone, take good care!!!!
[2023/11/10 14:31] Gemma (Gemma Cleanslate): /me APPLAUDS!!!
[2023/11/10 14:31] Mook Wheeler: clap clap clap clap clap clap!
[2023/11/10 14:31] Lorin Tone: BRAVO everyone in VAI!