

# “They Know. They’ve Lived It.”

Introducing the New *Voices of Experience* SCI Video Series

## VOICES OF EXPERIENCE

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Living with Spinal Cord Injury



# Disclosures

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**“Voices of Experience”** is a joint project of the Shirley Ryan AbilityLab and the Hill Foundation for Families Living with Disabilities.

It is partially funded by a grant from NIDILRR to the Midwest Regional Spinal Cord Injury Care System.



# Presenters

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No financial interests to disclose.



**Thea Flaum**

President,  
Hill Foundation



**Allen Heinemann, PhD**

Co-project director, Midwest Regional SCI Care System; Director, Center for Rehabilitation Outcomes Research, Shirley Ryan AbilityLab; Professor, Physical Medicine & Rehabilitation, Northwestern University; Licensed Clinical Psychologist, formerly provided direct services in SCI rehabilitation program



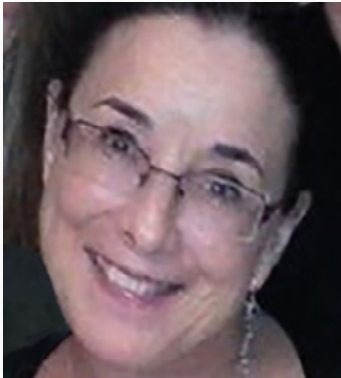
**Stephanie Lollino**

Vice President,  
Hill Foundation

# Panel

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No financial interests to disclose.



**Catherine Wilson,** PsyD, ABPP (Rp)

Private Practice

President, Section 2,

Women's Issues, 2022-2023

(Division 22, Rehabilitation Psychology)

Past President,

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SCI LTC & Outpatient Clinic

Certified Wound, Ostomy & Continence Nurse

LGBTQ+ Veteran Care Coordinator

LGBTQ+ SEP Manager

Professional Advisory Group Chair

Hospital Falls Committee Co-Chair

# Learning Objectives

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At the conclusion of this activity, participants will be able to:

1. Discover a new, easily accessible video and Internet resource for SCI patients
2. Discuss new ways to open conversations about important subjects with SCI patients
3. Analyze the value of personal experiences — how do they lead the way?





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# New 10-Part Video Series

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## For SCI Model Systems In-Hospital TV Networks

For people with *new*  
spinal cord injuries

Featuring people  
who have been  
*living with spinal  
cord injuries for years*







Nobody understands what you're going through  
like someone who's already been there



# Here's the Problem:

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## Communication with Patients and Families

All members of the rehabilitation team have a role

- Explaining injury and neurological condition
- Prognosis
- Expectations
- Teaching and Training



# Finding the Solution

## Motivation for This Project

- Psychosocial adaptation during inpatient rehabilitation can be challenging
- Physicians, nurses, psychologists, social workers, chaplains — all serve an important professional role in helping patients anticipate a life that's worth living



# Finding the Solution

- We lack the authentic, first-person experience of living with disability
- Only patients and their families live this experience
- AbilityLab has a long-standing collaborative relationship with the Hill Foundation and FacingDisability, which produces excellent first-person video accounts of life after SCI





# Finding the Solution

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## **Project Goal**

- Enhance the psychosocial adaptation of persons with new SCI and their families by producing a set of videos focused on common concerns

## **Project Aims**

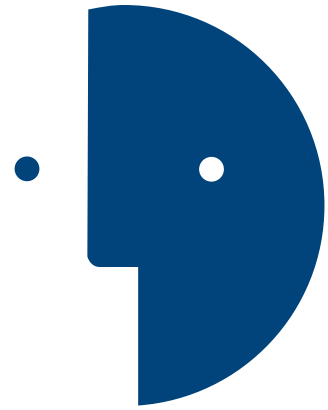
- Create an education resource for use during inpatient rehabilitation by patients and their families
- Provide a discussion guide for SCI rehabilitation clinicians
- Provide access via the in-house video networks used by SCIMS hospitals
- Share the video resource widely





YOU ARE NOT ALONE  
**Coping With Spinal Cord Injury**

Explore over 2,000 videos from our  
unique video library of family experiences



facingdisability.com

for families facing spinal cord injuries

## **VIDEO 1: Intro**



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## VIDEO 2: Preview



# Voices of Experience

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## 10-part series

- What was your greatest fear at first?
- What was the hardest part of the first days in the hospital?
- What do you wish you had known at the beginning?
- How do you handle anger?
- How do you handle guilt?
- Men: What about sex and dating?
- Women: What about sex and dating?
- How do I deal with my friends?
- How do I deal with my family?
- Can I still participate in sports?



# Panel

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## VIDEO 3: What was your greatest fear?





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## VIDEO 4: How do you handle anger?





# Voices of Experience

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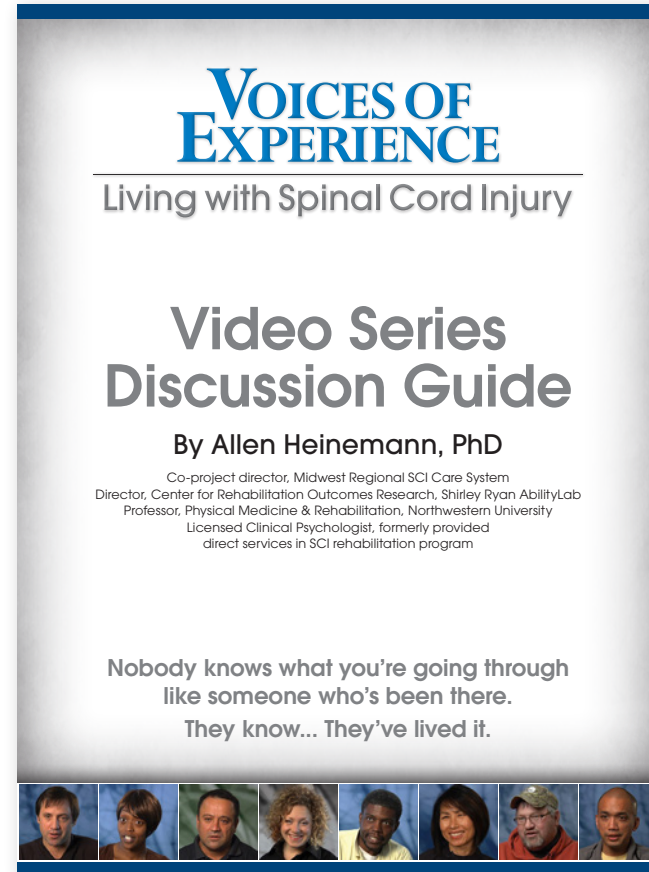
## 10-part series

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- Can I still participate in sports?

# Discussion Guide

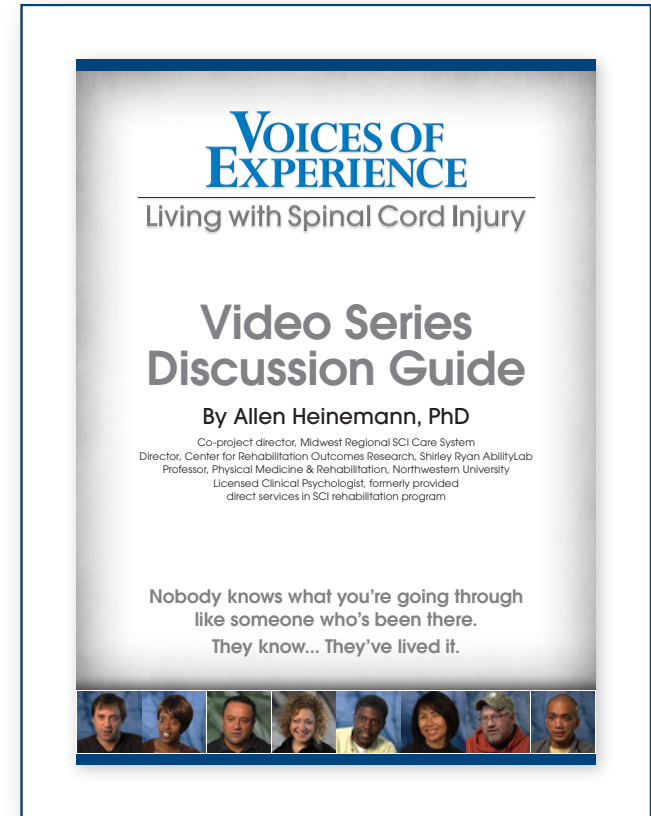
**By Allen Heinemann, PhD**

Shirley Ryan AbilityLab  
Northwestern University



# What are the Goals for “Voices of Experience”?

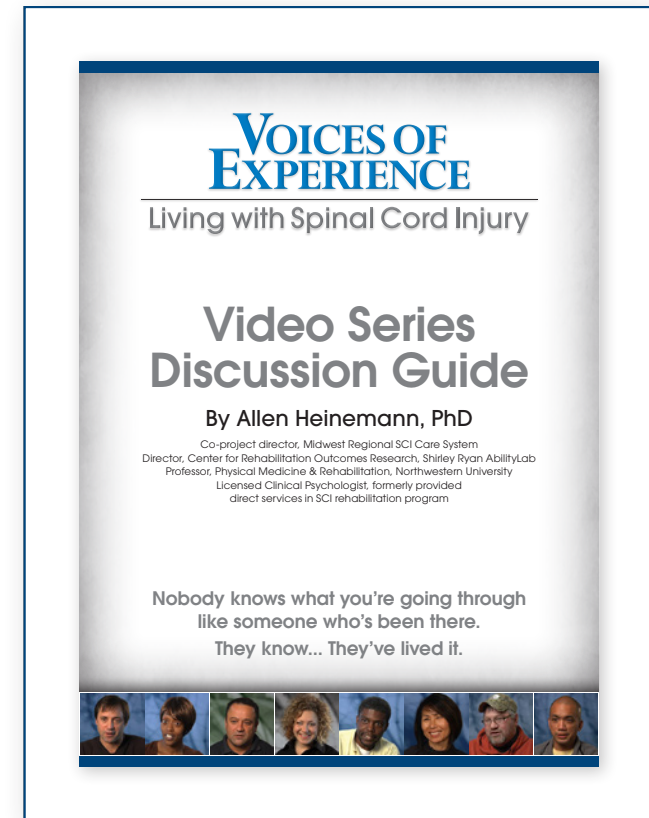
- Create an atmosphere that supports discussion of emotionally-laden topics
- Promote discussion of topics related to adjustment following SCI
- Encourage resumption of participation in valued activities





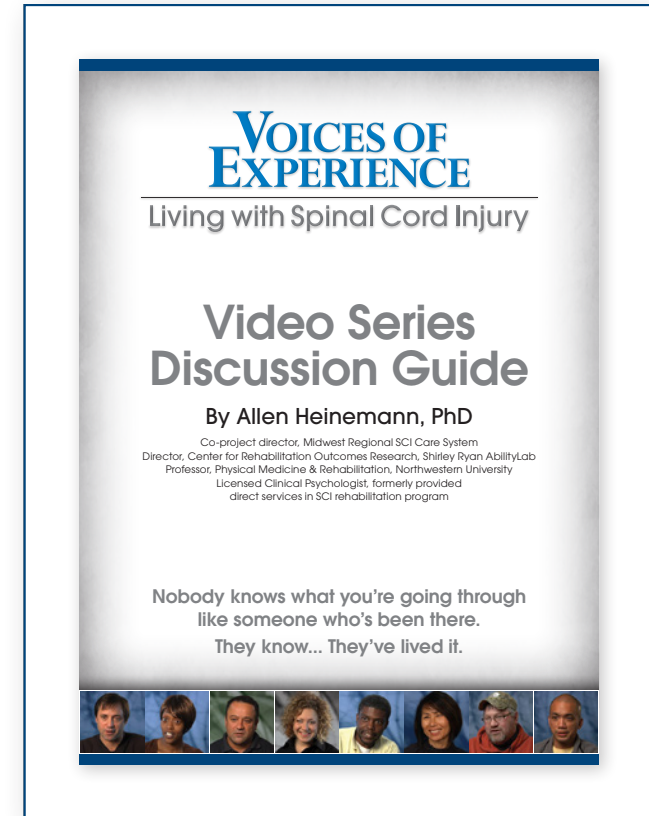
# How can I use the Discussion Guide?

- During patient meetings with therapeutic recreation staff and during regularly scheduled patient education sessions
- Patients may view the videos via web streaming
- It may be helpful for psychology or patient-family support staff to determine when patients are ready to view the videos
- Staff members with mental health training who have established rapport with patients are in an ideal position to lead discussions of the video series



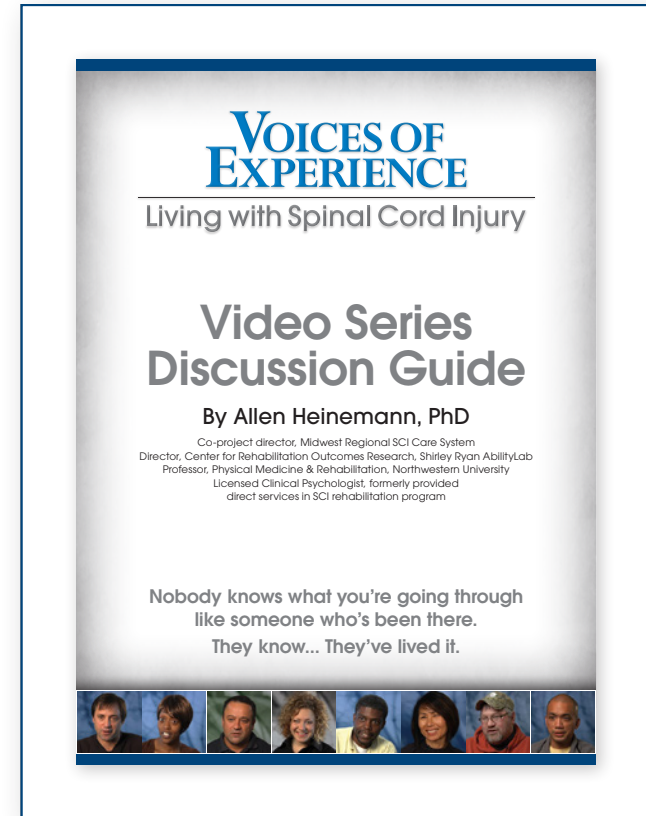
# Sample Discussion Questions

- What is your reaction to this video?
- What was it like for you to watch that?
- What sort of thoughts or feelings did it bring up?
- What spoke to you in terms of your experience?
- Did one person's interview stand out for you?
- If yes, which one? Why?
- What topic or issue was most relevant to you? Why?
- Was there anything that surprised you?
- What questions do you have about the topics discussed?



# After-Video Discussions

- Dealing with the medical, social, and vocational consequences of spinal cord injury can be challenging
- Grief and anger reactions are common
- Referral to mental health professionals is critical when reactions are extreme or prolonged





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## VIDEO 5: Can I still participate in sports?





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To watch and download the 10-part series, go to:  
[facingdisability.com/voices-of-experience-videos](http://facingdisability.com/voices-of-experience-videos)



# How to Claim CE Credit

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If you would like to receive continuing education credit for this activity, please visit:

**[pva.cds.pesgce.com](http://pva.cds.pesgce.com)**





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