

2018 Educational Conference and Expo September 2-5, 2018 New Orleans Marriott





Passion, Purpose and Possibilities in SCI/D

## Voices of Experience

SCI Video Series Features Real-Life Stories

### **Presenters**

No financial interests to disclose.



**Thea Flaum**President, Hill Foundation



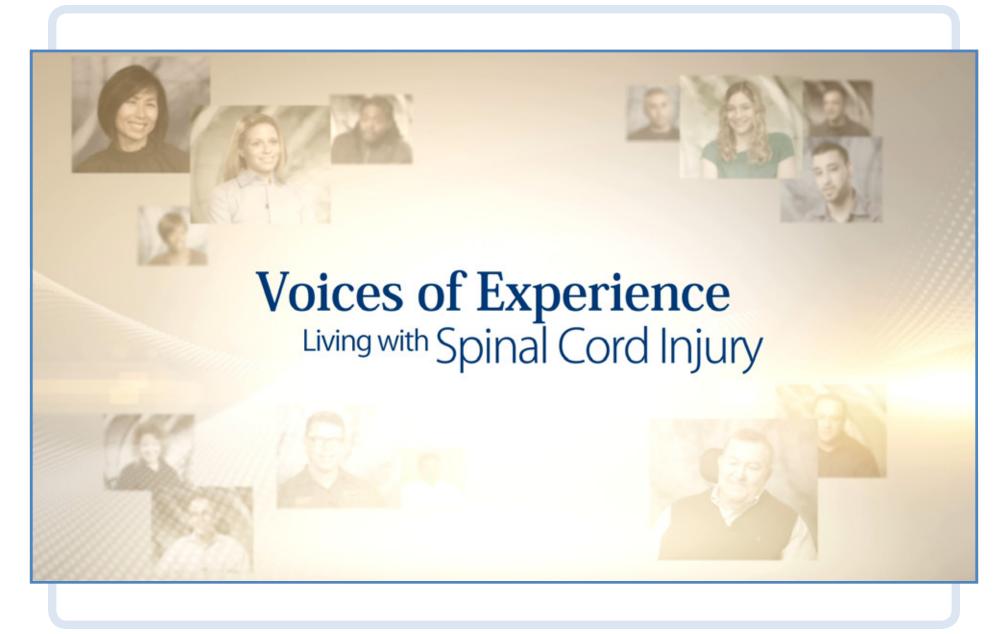
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## **New Video Series**

For SCI Model Systems In-Hospital Television Networks



## Here's the Problem:

#### **Communication with Patients and Families**

All members of the rehabilitation team have a role

 Explaining injury and neurological condition

- Prognosis
- Expectations
- Teaching and Training



## Here's the Problem:

#### What do Patients and Families Hear?

- Educational level
- Health literacy
- Prior experience with healthcare system
- Time since injury



## Here's the Problem:

#### **Delivering the Message**

We have different communication styles

- Personality
- Experience
- One size does not fit all



#### Midwest Regional Spinal Cord Injury Care System

One of the 14 hospitals comprising the National SCI Model Systems

#### **NSCIMS** Goals:

- Demonstrate excellence in SCI rehabilitation
- Contribute to a national database documenting patient outcomes
- Conduct a site-specific project
- Collaborate in multi-site research modules
- Participate in knowledge translation activities



#### **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



- 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



#### **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 via YouTube

#### **Project Methods**

 Conduct focus groups with SCI clinicians to select subjects for videos

 Review FacingDisability's extensive video library

 Select patients with diverse backgrounds and injury experience

 Emphasize coping and resilience



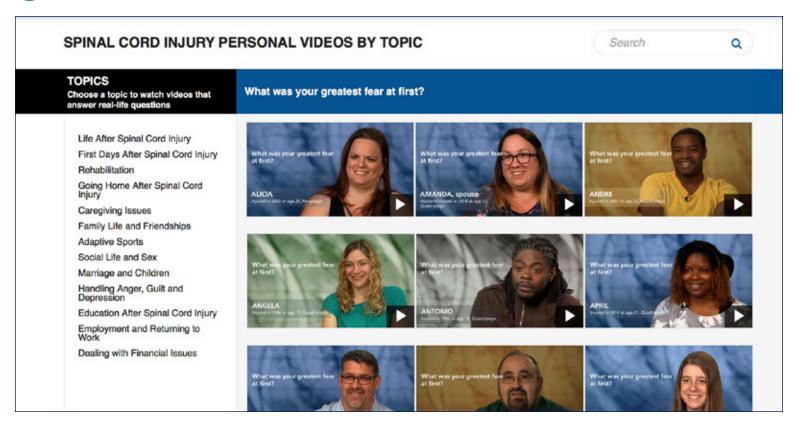






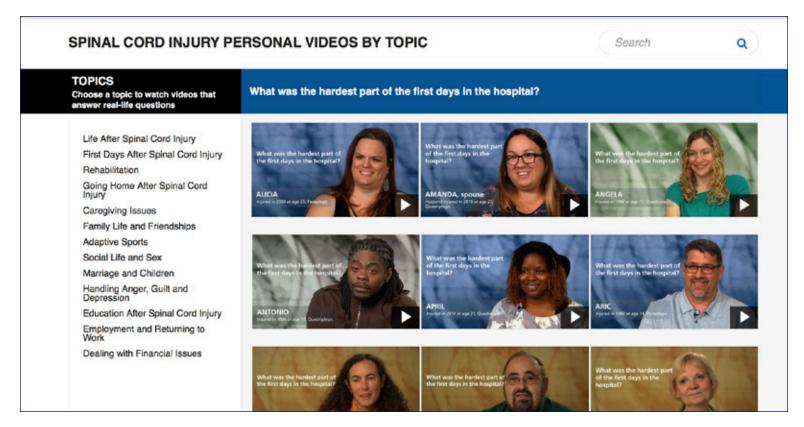
**VIDEO 1: INTRO** 

## "What was your greatest fear at first?"





# "What was the hardest part of the first days in the hospital?"





## **Top Ten Topics**

- 1. What was your greatest fear at first?
- 2. What was the hardest part of the first days in the hospital?
- 3. What do you wish you had known at the beginning?
- 4. Can I still have sex? (Men)
- 5. Can I still have sex? (Women)
- 6. Can I still have children?
- 7. How do you handle anger?
- 8. How do you handle guilt?
- 9. Can I still participate in sports?
- 10. How do I deal with my friends and family?



## **Disclosures**

"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.

## **Accreditation Statement**

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of the New Jersey of Academy of Family Physicians, the Firm, and ASCIP. The New Jersey Academy of Family Physicians is accredited by the ACCME to provide continuing medical education for physicians.

The New Jersey Academy of Family Physicians designates this live activity for a maximum of 31 AMA PRA Category 1 Credit(s).<sup>TM</sup>

Physicians should claim only the credit commensurate with the extent of their participation in the activity.

## **Learning Objectives**

- Discover a new, easily accessible resource for hospitalized SCI patients
- Discuss the subjects of greatest concern to newly injured patients
- Analyze the value of personal experiences do they lead the way?

## Obtaining CME/CE Credit

#### Credit is only given to attendees who:

- Successfully complete the entire course/session
- Evaluate the course by clicking on the link in an email sent to them
- After you have completed the evaluation, an email will automatically be generated to you with a link to print your certificate
- The evaluation system will close 30 days after the date of the conference

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For links to the videos:

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