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GATEWAY **TO THE FUTURE**

Sexuality and Spinal Cord Injury: The Need for Information and Support after SCI

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Sex After Spinal Cord Injury: Still a Hush-Hush Subject

FacingDisability.com: The Changing Face
of Spinal Cord Injury Education and Support

Faculty

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facingdisability.com

for families facing spinal cord injuries



Disclosures

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Sara J. Klaas, MSW, C-ASWCM

has no financial interest to disclose.

Thea Flaum

has no financial interest to disclose.



Today's Learning Objectives

- Discuss the importance of sexuality education and support for those affected by SCI
- Describe the need for continuous and relevant information specific to sexuality post-SCI
- Offer an important resource for people with SCI, their family, friends, and healthcare providers



Background...

Spinal cord injury is sudden and life changing

Life is turned upside down

- Entire Family
- Friends
- Community

Coping with the injury

- Physical
- Psychological
- Social
- Financial



Trauma, Hospitalization, & Rehab

Balancing Physical and Psychological Needs

- Level of injury
- Immediate medical concerns
- Treatment, meds, rehab
- Complications – pain, spasticity, UTI's, blood clots, pressure ulcers, autonomic dysreflexia

Emotional Shock

- This can't be happening to me

Denial vs. Hope

- This is only temporary



Trauma, Hospitalization, & Rehab

Initial Goals

- Impart knowledge of new injury
- Enhance level of independence
- Prepare for rejoining pre-injury activities including work or education
- Return to the community as soon as possible

Focus is, primarily, on the injured individual

- Shorter lengths of stay



But What About Sexuality...

Early after injury, people with SCI and their families begin asking questions

- Relationships & Attractiveness
- Sexual Experiences
- Ability to Conceive
- Future Parenting



The Importance of Sexuality & Reproduction

- Perhaps, more than any other factor, sexuality influences our feelings about ourselves & our relationships
- Encompasses our sense of self, biological make-up, relationships, moral & cultural beliefs, and the way we relate in society
- Consistently identified as one of the most important topics for those with SCI



The Importance of Sexuality & Reproduction after SCI

- Life does not end after SCI – nor does the opportunity for intimacy and a satisfying sex life
- Medical knowledge has advanced – insufficient without addressing QOL
- Sexuality needs to be addressed in an organized, nonjudgmental manner during rehabilitation and as part of life-long follow-up

(Consortium for SCI Medicine; Clinical Practice Guidelines 2010)



The Healthcare Provider Role

- Critical role in ensuring access to information & services to promote healthy sexual adjustment
- Must be knowledgeable & comfortable
- Ability to assess readiness
- Ability to refer for additional information, support, peer connections, & more...



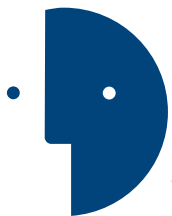
FacingDisability.com

- Cutting edge, internet-based project
- Decreased isolation, educate, & support
- Connect with experts, peers & family members
- Instantly available



After an SCI, the Family Often Has a Sense of Isolation

- 10,000-12,000 U.S. spinal cord injuries per year
- Half aged 16-30 at time of injury
- 80 percent male
- Half result in quadriplegia/tetraplegia
- 270,000 people now living with SCI



After only...

- 11 hospital days
- 36 rehab days

8 out of 10 people
with SCI return home



Now what???





facingdisability.com

for families facing spinal cord injuries

VIDEO 1: INTRO

Collecting Life Experiences In Coping With SCI

- What do family members need to know right away?
- What are the most important questions?



Look Who's Talking

More than 100 people: mothers, fathers, siblings, spouses, children and people with SCI themselves

Recommendations from SCI professionals

- Rehabilitation Institute of Chicago
- Shriners Childrens Hospital – Chicago
- Schwab Rehabilitation Hospital – Chicago
- Magee Rehabilitation Hospital – Philadelphia
- Marianjoy Rehabilitation Hospital – Chicago



Close-Ups are Powerful



Keep It Short

The internet is an impatient medium

1,400 videos today...

90 percent of them are

LESS THAN ONE MINUTE LONG





Search Facing Disability



T T

Watch Videos

Resources

Forums

Peer Counseling

About

Blog

Donate

Spinal Cord Injury Topics And Questions

Categories

- First Days After SCI
- SCI Rehabilitation
- SCI Financial Issues
- Going Home After SCI
- SCI Caregiving
- Education After SCI
- Adaptive Sports
- Employment After SCI
- Relationships After SCI
- Social Life & Sex After SCI
- Marriage & Children After SCI
- Feelings After SCI
- Life After SCI



Click on a question in the list below, or select a category on the left to filter your search.

First Days After SCI

- [What was the hardest part of the first days in the hospital?](#)
- [How did you develop an understanding of the injury?](#)
- [What was your greatest fear at first?](#)
- [How did family members respond to the news?](#)
- [What personal support was most helpful to you?](#)
- [How did you deal with stress at first?](#)
- [What do you wish you had known at the beginning?](#)

SCI Rehabilitation

- [What were the important milestones in rehabilitation?](#)
- [What was the hardest part of rehabilitation?](#)

Employment After SCI

- [What kind of work do you do?](#)
- [How did you handle going back to work?](#)

Relationships After SCI

- [How have your family relationships changed?](#)
- [How has your relationship with your son or daughter changed?](#)
- [How have your friendships changed?](#)
- [What's important for parents to understand?](#)
- [What's important for family and friends to understand?](#)
- [What's the hardest part about having a disabled family member?](#)

Spinal Cord Injury Questions & Answers | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/spinal-cord-injury-questions-and-answers

facingdisability.com
for families facing spinal cord injuries

Watch Videos Resources

Spinal Cord Injury Topics

Categories

- First Days After SCI
- SCI Rehabilitation
- SCI Financial Issues
- Going Home After SCI
- SCI Caregiving
- Education After SCI
- Adaptive Sports
- Employment After SCI
- Relationships After SCI
- Social Life & Sex After SCI
- Marriage & Children After SCI
- Feelings After SCI
- Life After SCI

Click on a question

First Days After SCI

What was the hardest part of life in the hospital?

How did you develop coping strategies?

What was your greatest challenge?

How did family members cope?

What personal support did you need?

How did you deal with the physical challenges?

What do you wish you had known?

SCI Rehabilitation

What were the important milestones in rehabilitation?

What was the hardest part of rehabilitation?

What's important for parents to understand?

What's important for family and friends to understand?

What's the hardest part about having a disabled family member?

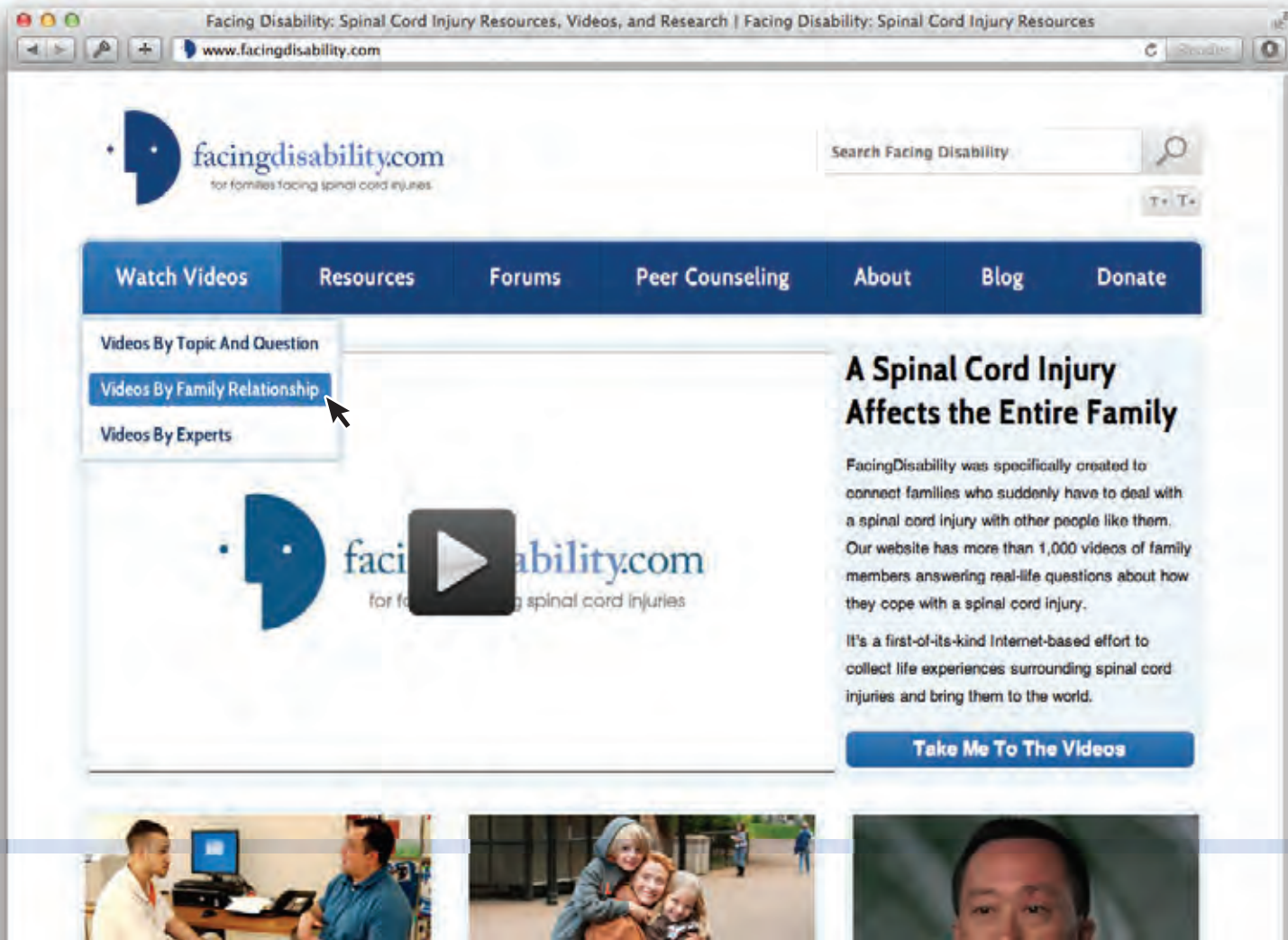
Donate

Search

T T

Lighter

How to Find Who You're Looking For



The screenshot shows the homepage of www.facingdisability.com. The browser's address bar displays the website's name and URL. The page features a navigation bar with links: Watch Videos, Resources, Forums, Peer Counseling, About, Blog, and Donate. A dropdown menu under 'Watch Videos' is open, showing options: 'Videos By Topic And Question', 'Videos By Family Relationship' (highlighted with a mouse cursor), and 'Videos By Experts'. Below the navigation bar, there is a large video player area with the Facing Disability logo and a play button. To the right of the video player, there is a featured article titled 'A Spinal Cord Injury Affects the Entire Family' with a brief description and a 'Take Me To The Videos' button. At the bottom of the page, there are three small thumbnail images: a man in a white shirt, a family of four, and a close-up of a man's face.

Facing Disability: Spinal Cord Injury Resources, Videos, and Research | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com

facingdisability.com
for families facing spinal cord injuries

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

Videos By Topic And Question
Videos By Family Relationship
Videos By Experts

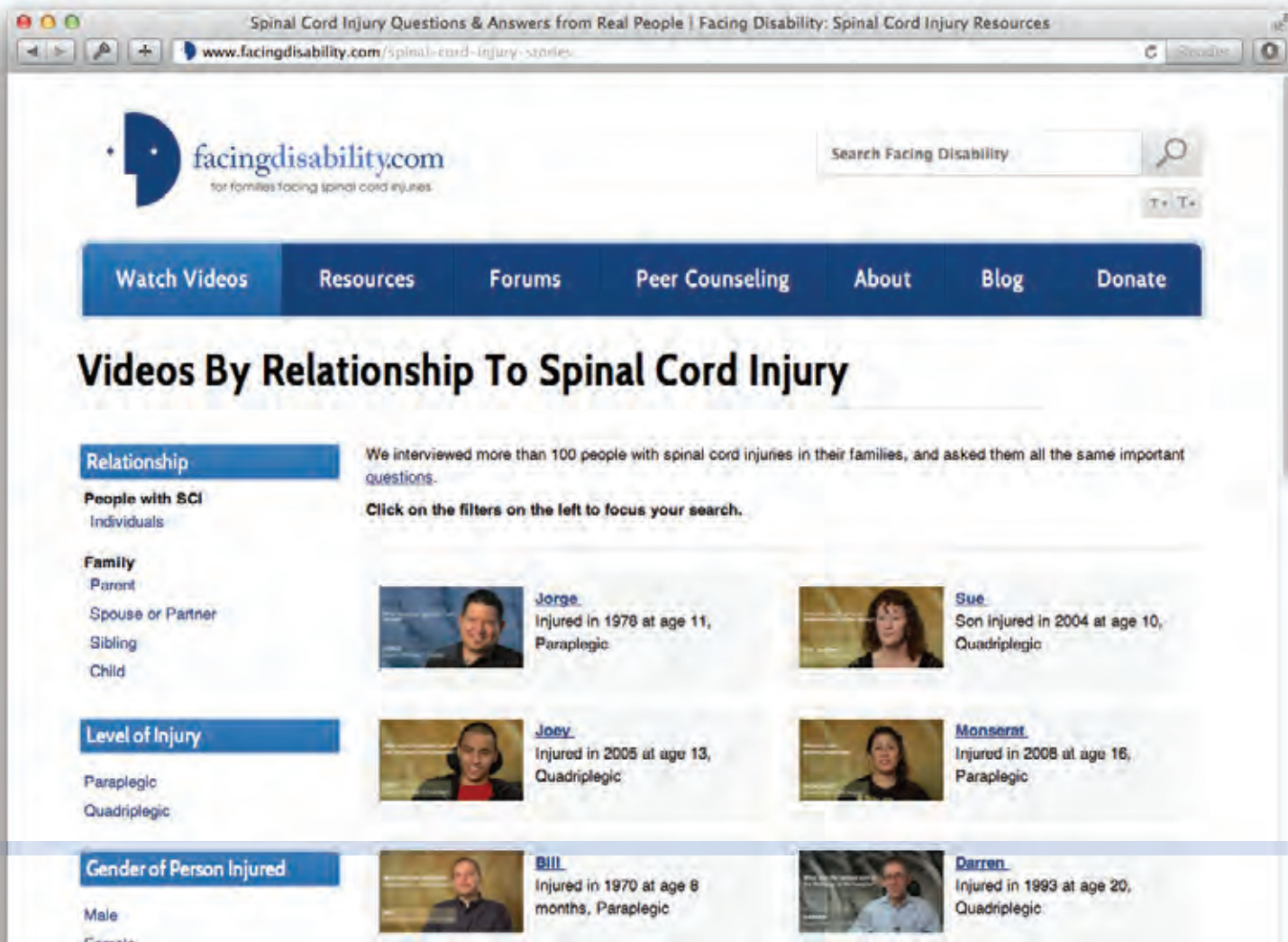
A Spinal Cord Injury Affects the Entire Family

FacingDisability was specifically created to connect families who suddenly have to deal with a spinal cord injury with other people like them. Our website has more than 1,000 videos of family members answering real-life questions about how they cope with a spinal cord injury.

It's a first-of-its-kind Internet-based effort to collect life experiences surrounding spinal cord injuries and bring them to the world.

Take Me To The Videos

How to Find Who You're Looking For



The screenshot shows a web browser window with the URL www.facingdisability.com/spinal-cord-injury-stories. The page features the Facing Disability logo and a search bar. A navigation bar includes links for Watch Videos, Resources, Forums, Peer Counseling, About, Blog, and Donate. The main heading is "Videos By Relationship To Spinal Cord Injury".

Relationship

We interviewed more than 100 people with spinal cord injuries in their families, and asked them all the same important questions.

Click on the filters on the left to focus your search.

People with SCI

Individuals

Family

- Parent
- Spouse or Partner
- Sibling
- Child

Level of Injury

- Paraplegic
- Quadriplegic

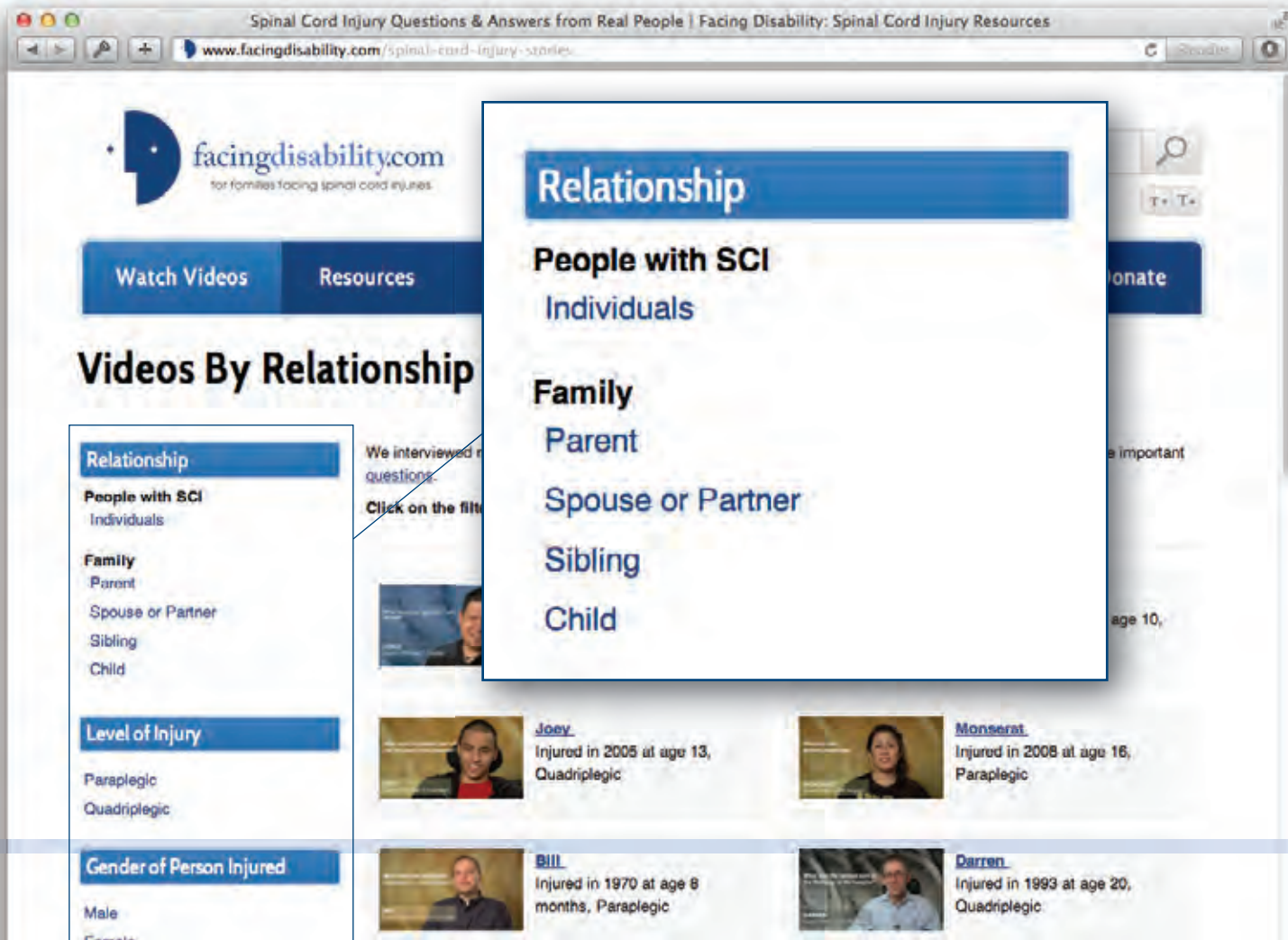
Gender of Person Injured

- Male
- Female

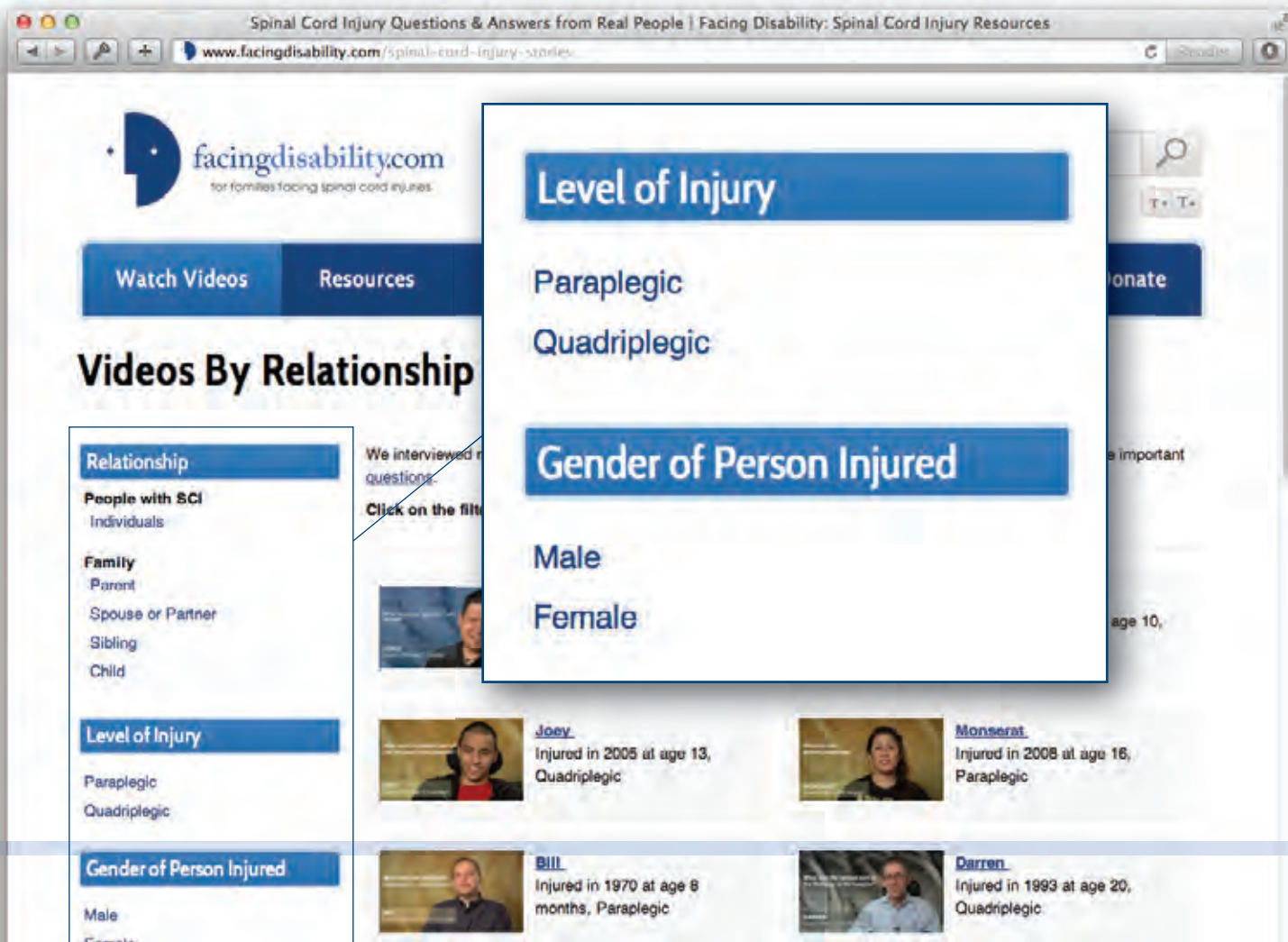
Video Results:

Name	Relationship	Age at Injury	Level of Injury
Jorge	Parent	11	Paraplegic
Sue	Parent	10	Quadriplegic
Joey	Parent	13	Quadriplegic
Monserat	Parent	16	Paraplegic
Bill	Parent	8 months	Paraplegic
Darren	Parent	20	Quadriplegic

How to Find Who You're Looking For



How to Find Who You're Looking For



The screenshot shows the website www.facingdisability.com with the title "Spinal Cord Injury Questions & Answers from Real People | Facing Disability: Spinal Cord Injury Resources". The page features a sidebar with filters and a main content area with a large overlay menu.

Facing Disability Logo: facingdisability.com for families facing spinal cord injuries

Navigation: Watch Videos, Resources

Videos By Relationship

Relationship Filter:

- People with SCI
- Individuals
- Family
 - Parent
 - Spouse or Partner
 - Sibling
 - Child

Level of Injury Filter:

- Paraplegic
- Quadriplegic

Gender of Person Injured Filter:

- Male
- Female

Main Content Area:

We interviewed real people with spinal cord injuries. Click on the filter to see more stories.

Stories:

- Joey**
Injured in 2005 at age 13, Quadriplegic
- Monserat**
Injured in 2008 at age 16, Paraplegic
- Bill**
Injured in 1970 at age 8 months, Paraplegic
- Darren**
Injured in 1993 at age 20, Quadriplegic

How to Find Who You're Looking For

The screenshot shows a web browser window with the URL www.facingdisability.com/spinal-cord-injury-stories. The page features a navigation bar with "Watch Videos" and "Resources" buttons. A sidebar on the left contains filters for "Relationship" (People with SCI, Family), "Level of Injury" (Paraplegic, Quadriplegic), and "Gender of Person Injured" (Male, Female). A central dropdown menu titled "Age at Injury" is open, showing options: 0-12, 13-18, 19-24, 25-35, and 36+. The main content area displays a grid of video thumbnails with associated names and injury details.

Age at Injury

- 0-12
- 13-18
- 19-24
- 25-35
- 36+

Relationship

- People with SCI
- Individuals
- Family
 - Parent
 - Spouse or Partner
 - Sibling
 - Child

Level of Injury

- Paraplegic
- Quadriplegic

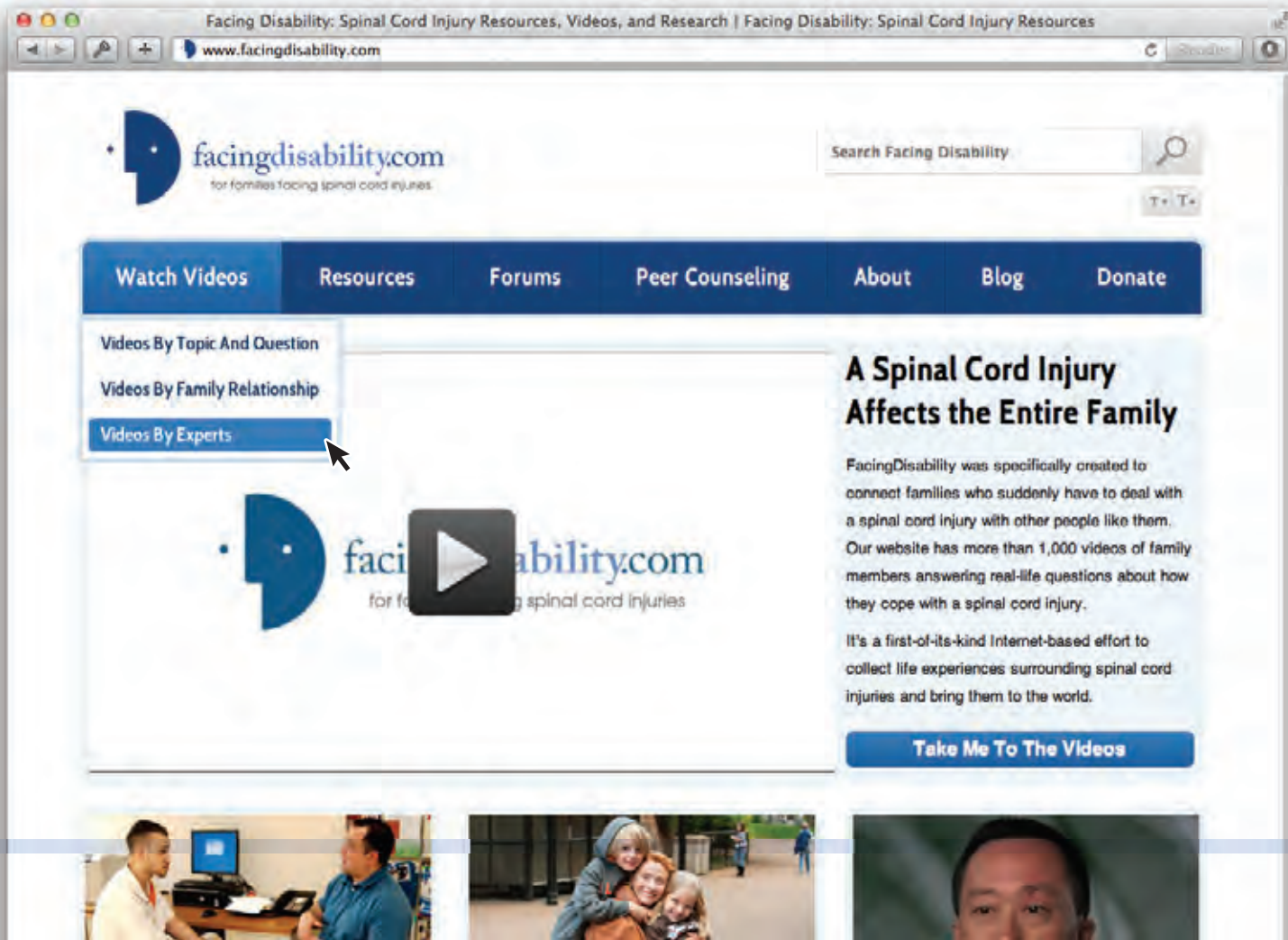
Gender of Person Injured

- Male
- Female

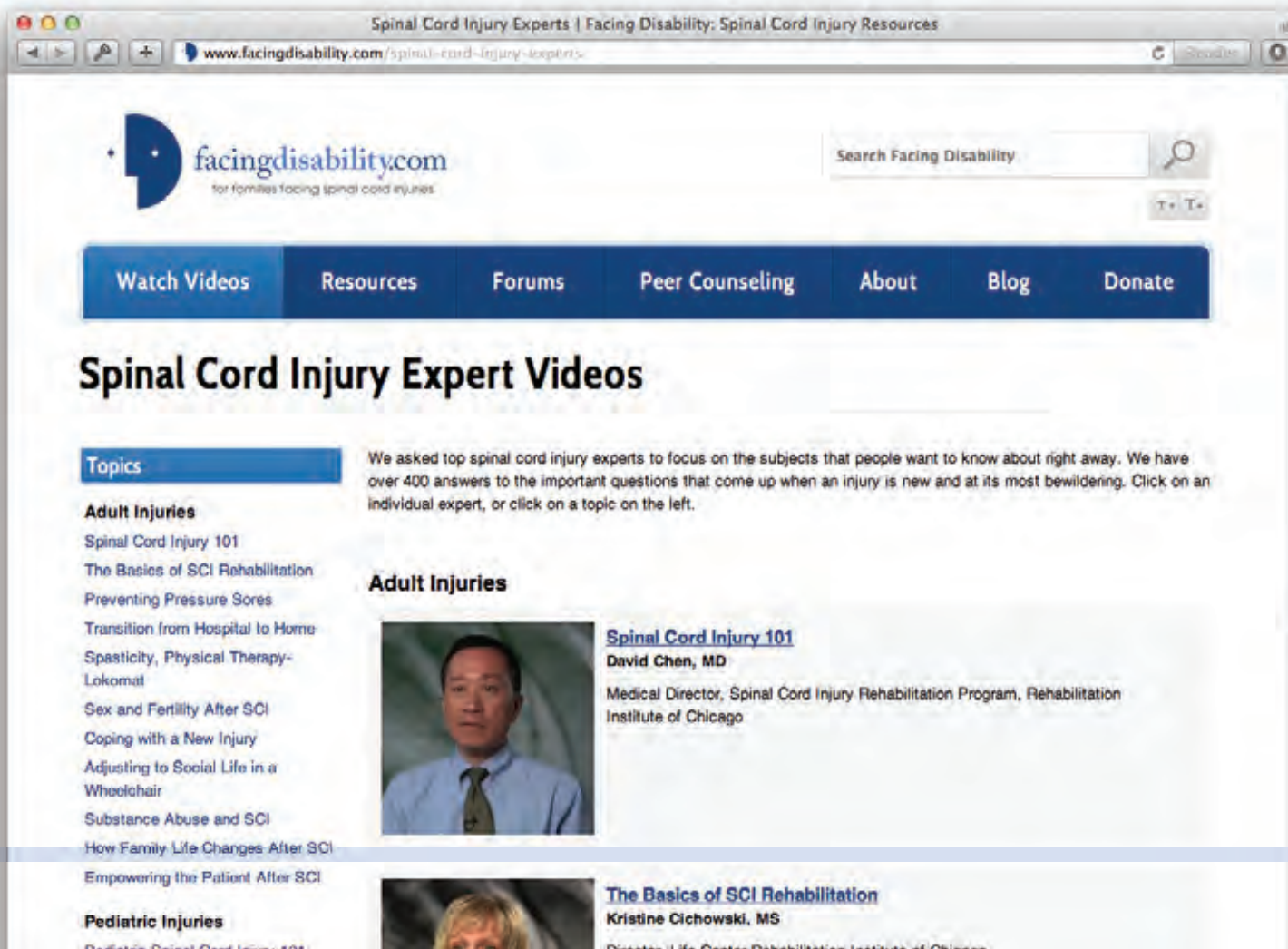
Video Grid:

Name	Injury Details
Jorge	Injured in 1978 at age 11, Paraplegic
Sue	Son injured in 2004 at age 10, Quadriplegic
Joey	Injured in 2005 at age 13, Quadriplegic
Monserat	Injured in 2008 at age 16, Paraplegic
Bill	Injured in 1970 at age 8 months, Paraplegic
Darren	Injured in 1993 at age 20, Quadriplegic

How to Find an Expert



How to Find an Expert



The screenshot shows a web browser window with the address bar displaying "www.facingdisability.com/spinal-cord-injury-experts". The page title is "Spinal Cord Injury Experts | Facing Disability: Spinal Cord Injury Resources". The logo for "facingdisability.com" is in the top left, with the tagline "for families facing spinal cord injuries". A search bar labeled "Search Facing Disability" is in the top right. A navigation bar contains links: "Watch Videos", "Resources", "Forums", "Peer Counseling", "About", "Blog", and "Donate". The main heading is "Spinal Cord Injury Expert Videos". Below it, a "Topics" section lists various subjects under "Adult Injuries" and "Pediatric Injuries". A featured video for "Spinal Cord Injury 101" by David Chen, MD, is highlighted, showing a portrait of the expert and his title as Medical Director at the Rehabilitation Institute of Chicago.

Spinal Cord Injury Experts | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/spinal-cord-injury-experts

facingdisability.com
for families facing spinal cord injuries

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

Spinal Cord Injury Expert Videos

Topics

Adult Injuries

- Spinal Cord Injury 101
- The Basics of SCI Rehabilitation
- Preventing Pressure Sores
- Transition from Hospital to Home
- Spasticity, Physical Therapy- Lokomat
- Sex and Fertility After SCI
- Coping with a New Injury
- Adjusting to Social Life in a Wheelchair
- Substance Abuse and SCI
- How Family Life Changes After SCI
- Empowering the Patient After SCI

Pediatric Injuries

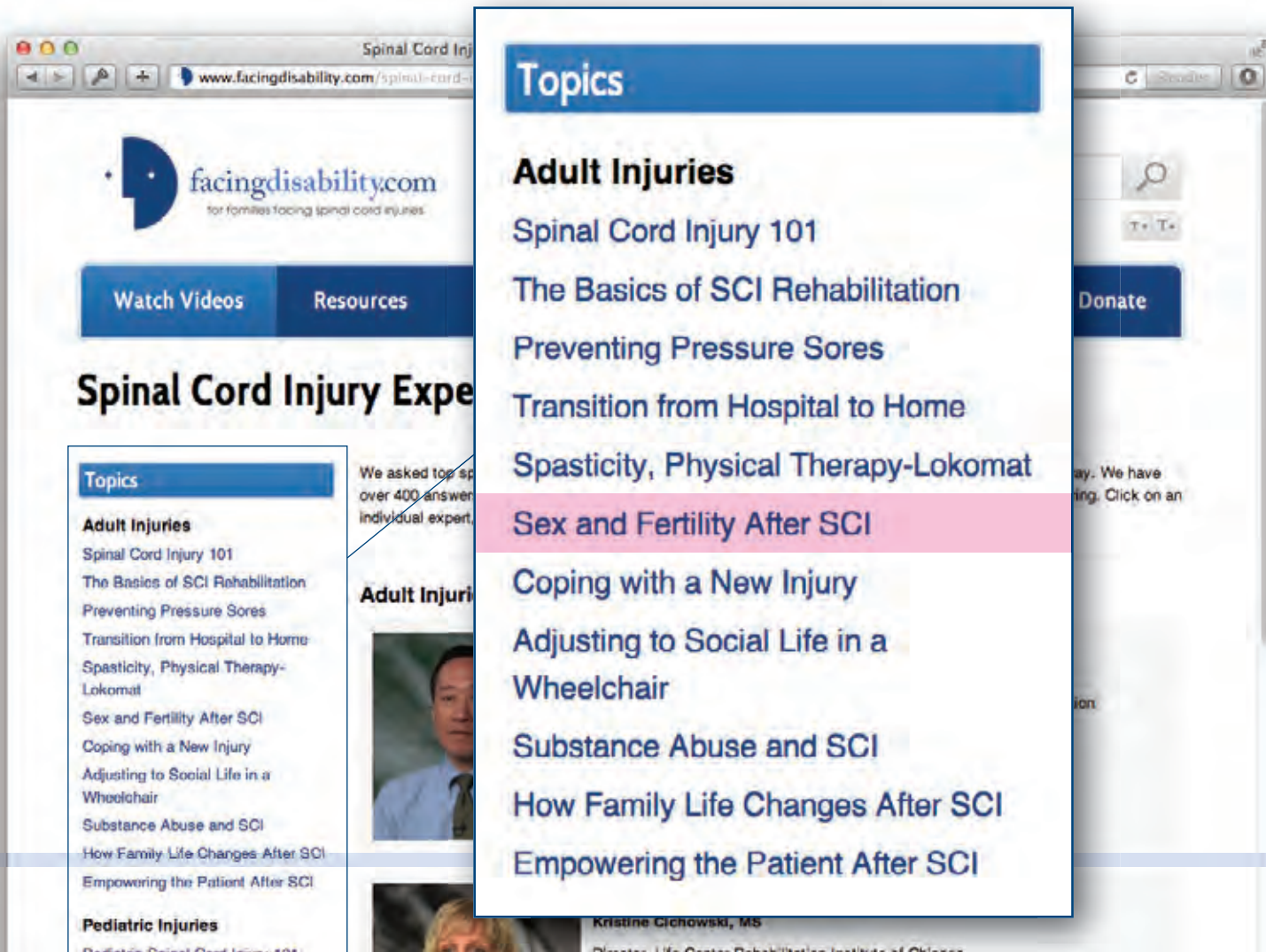
We asked top spinal cord injury experts to focus on the subjects that people want to know about right away. We have over 400 answers to the important questions that come up when an injury is new and at its most bewildering. Click on an individual expert, or click on a topic on the left.

Adult Injuries

Spinal Cord Injury 101
David Chen, MD
Medical Director, Spinal Cord Injury Rehabilitation Program, Rehabilitation Institute of Chicago

The Basics of SCI Rehabilitation
Kristine Cichowski, MS
Director, Life Center Rehabilitation Institute of Chicago

How to Find an Expert



What Are the Hot Topics?

Google Analytics (June 1, 2013 – May 31, 2014)

97,000 visitors

318,000 Page Views

21% = Sex, Social Life,
Fertility, Family Relationships



What Videos are They Watching?

Ooyala Content Analysis (June 1, 2013 – May 31, 2014)

45,000 video plays

700 hours

55-seconds = average video play

17% = Sex, Fertility,
Social Life, Relationships





facingdisability.com

for families facing spinal cord injuries

VIDEO 2: PERSONAL EXPERIENCES

What Expert Videos Are Most Watched?

“Sex and Fertility After Spinal Cord Injury”

Diane M. Rowles, MS, NP

Nurse Practitioner,
Spinal Cord Injury Program
Rehabilitation of Chicago

Diane Rowles accounts for
9% of all videos watched



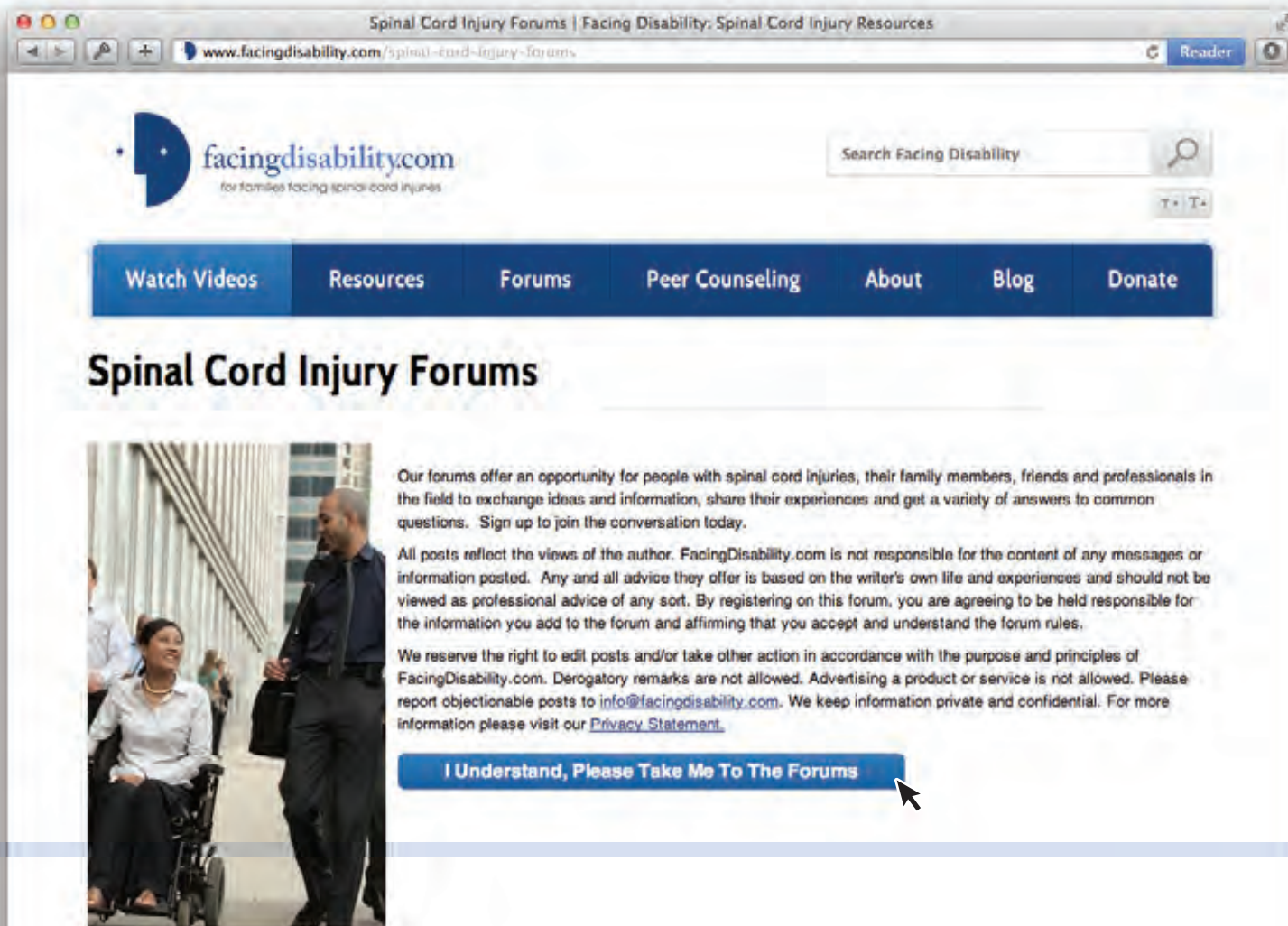


facingdisability.com

for families facing spinal cord injuries

VIDEO 3: DIANE ROWLES

Forums



The screenshot shows a web browser window with the address bar displaying "www.facingdisability.com/spinal-cord-injury-forums". The page features the "facingdisability.com" logo with the tagline "for families facing spinal cord injuries". A search bar labeled "Search Facing Disability" is located in the top right. Below the logo is a navigation menu with buttons for "Watch Videos", "Resources", "Forums", "Peer Counseling", "About", "Blog", and "Donate". The main heading is "Spinal Cord Injury Forums". To the left of the text is a photograph of a man in a dark shirt and trousers walking alongside a woman in a white shirt who is seated in a motorized wheelchair. They are outdoors, with a modern building featuring large glass windows in the background. To the right of the photo, there is a paragraph of introductory text about the forums, followed by a disclaimer and a registration notice. At the bottom of this section is a blue button with white text that reads "I Understand, Please Take Me To The Forums". A mouse cursor is pointing at this button.

Spinal Cord Injury Forums | Facing Disability: Spinal Cord Injury Resources


www.facingdisability.com/spinal-cord-injury-forums

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for families facing spinal cord injuries

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

Spinal Cord Injury Forums



Our forums offer an opportunity for people with spinal cord injuries, their family members, friends and professionals in the field to exchange ideas and information, share their experiences and get a variety of answers to common questions. Sign up to join the conversation today.

All posts reflect the views of the author. FacingDisability.com is not responsible for the content of any messages or information posted. Any and all advice they offer is based on the writer's own life and experiences and should not be viewed as professional advice of any sort. By registering on this forum, you are agreeing to be held responsible for the information you add to the forum and affirming that you accept and understand the forum rules.

We reserve the right to edit posts and/or take other action in accordance with the purpose and principles of FacingDisability.com. Derogatory remarks are not allowed. Advertising a product or service is not allowed. Please report objectionable posts to info@facingdisability.com. We keep information private and confidential. For more information please visit our [Privacy Statement](#).

I Understand, Please Take Me To The Forums

Forums


Popular Forum Discussions:

Should a spouse or partner
be a primary caregiver? = 485 views

I love him. I HATE his body. = 41 views



How to Find Resources



The screenshot shows a web browser window with the address bar displaying "www.facingdisability.com/spinal-cord-injury-resources". The page title is "Spinal Cord Injury Resources | Facing Disability: Spinal Cord Injury Resources". The website logo is "facingdisability.com" with the tagline "for families facing spinal cord injuries". A search bar is labeled "Search Facing Disability". A navigation bar contains links: "Watch Videos", "Resources", "Forums", "Peer Counseling", "About", "Blog", and "Donate". The "Resources" section is highlighted, showing a list of categories: "Short List", "Government Programs", "Family and Caregiver Support", "Financial Help", "Active Lifestyle", "Advocacy", "Employment and Education", "Adaptive Technology", "Recent Medical Research", "Good Things to Read", "SCI Facts and Figures", "Model System Rehab Hospitals", and "Pediatric Spinal Cord Injury". Below the categories, there are three images: a man and a woman at a table, a man at a computer, and a woman in a wheelchair. A text block states: "We selected more than 300 of the best spinal cord injury resources on the web. We designed it to help you find what you need quickly; the descriptions are written in plain English; every listing tells you 'Where to Start.'" Below this, there are two sections: "Short List" and "Adaptive Technology".

Spinal Cord Injury Resources | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/spinal-cord-injury-resources

facingdisability.com
for families facing spinal cord injuries

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

Resources

Categories

- Short List
- Government Programs
- Family and Caregiver Support
- Financial Help
- Active Lifestyle
- Advocacy
- Employment and Education
- Adaptive Technology
- Recent Medical Research
- Good Things to Read
- SCI Facts and Figures
- Model System Rehab Hospitals
- Pediatric Spinal Cord Injury

We selected more than 300 of the best spinal cord injury resources on the web. We designed it to help you find what you need quickly; the descriptions are written in plain English; every listing tells you "Where to Start."

Short List

These websites are good places to begin to learn about the core basics of spinal cord injuries. The Short List constitutes an introduction to spinal cord information, institutions and the disability community.

Adaptive Technology

Adaptive technology refers to products, devices or equipment, whether acquired commercially, modified or customized, that are used to maintain, increase or improve the functional capabilities of individuals with disabilities. These websites feature useful programs like

Peer Counseling



The screenshot shows a web browser window with the address bar displaying "www.facingdisability.com/peer_counseling/info/overview". The page title is "Peer Counseling for People With Spinal Cord Injuries | Facing Disability: Spinal Cord Injury Resources". The website logo is "facingdisability.com for families facing spinal cord injuries". A search bar is labeled "Search Facing Disability". A navigation menu includes "Watch Videos", "Resources", "Forums", "Peer Counseling", "About", "Blog", and "Donate". The main heading is "Peer Counseling Overview". On the left, a sidebar lists "Peer Counseling" (highlighted), "Overview", "Sign up", "How the Match-Up Work", "Starting the Conversation", "Tips for Success", and "Volunteer to be a Peer Counselor", followed by a "Sign in" button. The main content area features a photo of two men, one in a wheelchair, talking. Text explains that a peer counselor is someone who has "been there, done that" and offers emotional support and practical help. A blue button at the bottom says "Click Here To Sign Up Or Call 312-284-2525".

Peer Counseling for People With Spinal Cord Injuries | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/peer_counseling/info/overview

facingdisability.com
for families facing spinal cord injuries

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

Peer Counseling Overview

Peer Counseling

- Overview
- Sign up
- How the Match-Up Work
- Starting the Conversation
- Tips for Success
- Volunteer to be a Peer Counselor

Sign in



A "peer counselor" is someone who has "been there, done that" and who has had several years of real-life experience in dealing with a spinal cord injury similar to yours.

The communication between you is through written messages in a private conversation on the FacingDisability website. The people on both sides are anonymous. The service is free.

Our peer counselors are not trained professionals. They are people like you who have encountered the same issues and problems that you are now facing. They are unpaid volunteers who have agreed to use their knowledge and experience to offer emotional support and practical help.

We want to connect you with someone who is as much like you as possible. Another mother, father, wife, husband, sister, brother, or person with a spinal cord injury whose profile is similar to yours. Nobody understands what you're going through the way someone who has actually been there.

Click Here To Sign Up Or Call 312-284-2525

[Home](#) [Blog](#)

[Mission, Vision, and Questions](#)

A spinal cord injury affects the entire family



facingdisability.com

for families facing spinal cord injuries

VIDEO 4: SEX ADVICE AND INFORMATION

Henry B. Betts, MD

Physiatrist, educator,
advocate, humanitarian

Dr. Betts has devoted his
career to improving the lives
of people with disabilities



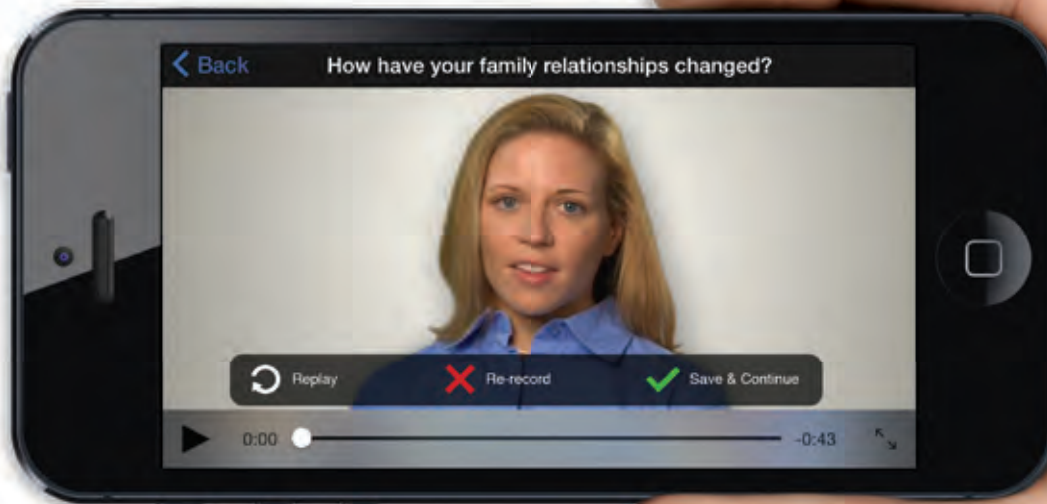
“Will anyone ever love me?”

“Will anyone ever want to touch me?”



Share Your Story with Our New Video App

Record your own videos with your iPhone or iPad and send them to us



A Spinal Cord Injury Affects The Entire Family



 facingdisability.com

for families facing spinal cord injuries

