Coronavirus / COVID-19

STAY HEALTHY

Help Individuals with Spinal Cord Injury, Traumatic Brain Injury, and Burn Injury Stay Healthy during the COVID-19 Pandemic

Model Systems Knowledge Translation Center (MSKTC)

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American Institutes for Research

Disclosures

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 NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).
 The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.



Learning Objectives

- Use the free research-based resources developed by the Model Systems Knowledge Translation Center (MSKTC) to help individuals living with spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury to stay healthy during the COVID-19 pandemic
- Understand how the MSKTC has worked with Model System researchers to apply a knowledge translation (KT) framework to make these resources useful to the end-users
- Understand principles in effectively communicating health information to support individuals with SCI, TBI, and burn injuries



Session Overview

- Model Systems Knowledge Translation Center (MSKTC) background
- Example MSKTC resources to help individuals with spinal cord injury (SCI), traumatic brain injury (TBI) and burn to stay healthy during the COVID-19 pandemic
- KT strategies to communicate health information and to ensure high quality and usefulness of the MSKTC resources
- Tour of the MSKTC website
- Questions and discussion



MSKTC Background

- Funded by National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, US Department of Health and Human Services
- Provides knowledge translation (KT) supports to the Model System Center Programs
 - 14 Spinal Cord Injury (SCI) Model System Centers with 1 Data
 Center
 - 16 Traumatic Brain Injury (TBI) Model System Centers with 1
 Data Center
 - 4 Burn Model System Centers with 1 Data Center



Goals of the MSKTC

- Enhance the relevance and visibility of Model Systems research
- Communicate Model Systems research effectively to stakeholders



Main Audiences of MSKTC

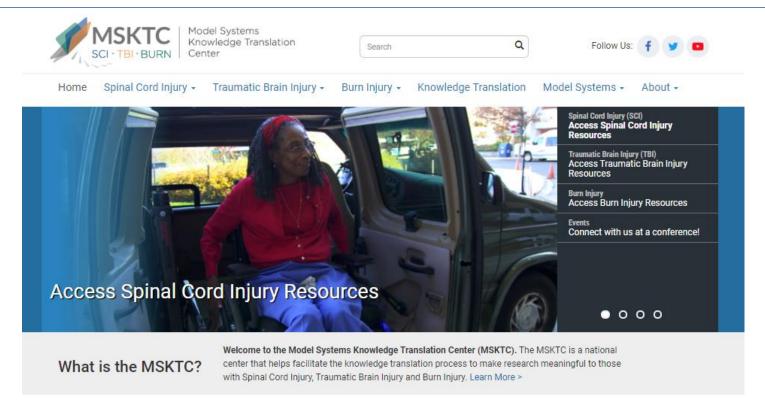
- Individuals with SCI, TBI, and Burn and Their families
- Practitioners and Clinicians
- Policymakers and Advocacy Organizations
- Researchers





Model Systems Knowledge Translation Center

www.msktc.org



INJURY TYPE & RESOURCES







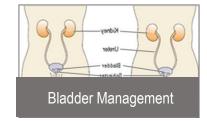


Example MSKTC Resources to Help Stay Healthy During the COVID-19 Pandemic

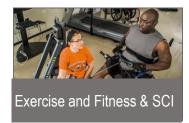


Example SCI Resources to Help Stay Healthy during the Pandemic











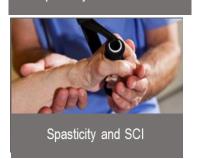
















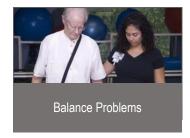
Example TBI Resources to Help Stay Healthy during the Pandemic





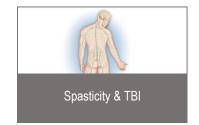








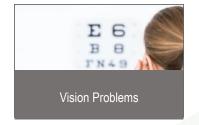






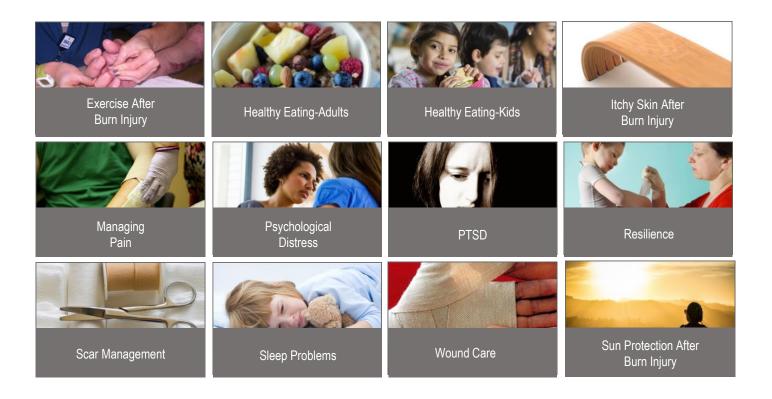








Example Burn Resources to Help Stay Healthy during the Pandemic





Links to the MSKTC COVID-19 Resources

- Web page: https://msktc.org/example-msktc-resources-help-stay-healthy-during-covid-19-pandemic
- Example MSKTC SCI COVID-19 resource flyer: https://msktc.org/sites/default/files/MSKTC-SCI COVID-19-Resource-Flyer.pdf
- Example MSKTC TBI COVID-19 resource flyer: https://msktc.org/sites/default/files/MSKTC-TBI COVID-19-Resource-Flyer.pdf
- Example MSKTC Burn COVID-19 resource flyer: https://msktc.org/sites/default/files/MSKTC-Burn COVID-19-Resource-Flyer.pdf



Different Types of MSKTC Consumer Resources



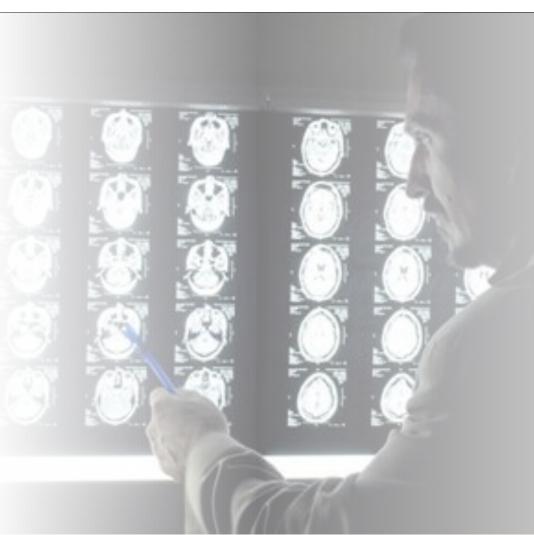














Factsheets in English and Spanish



Bowel Function After Spinal Cord Iniury



March 2015

This fact sheet tells you about why a bowel program can improve your quality of life.

What you need to know

- A spinal cord injury can lead to bowel p You may have problems movin
 - You may pass a stool when you These problems can cause pair
 - When eating, you may feel full t
 - Bowel problems can contribute being able to control bowel mov

A bowel program can help you to contro avoid other problems and perhaps bowe

Understanding your box

Your stomach and small intestine pull nu give you energy. The rest of the food bestool in your colon and rectum and leave through and out of your body is known a process may be tough for you. For exam have a difficult time passing stools. This "constination." Or you may not be able to you pass a stool. This is called "stool inco

Spinal cord injuries may cause tightness looseness (flaccidity) in the muscles of th sphincters, and pelvic floor. The degree of looseness may be related to the severity completeness and level of your injury. If y above level T11/T12, then the muscles of sphincters and pelvic floor may be tight, w constipation. If your injury is level T11/T12 these muscles may be loose, which leads incontinence. People with incomplete spin tend to have more muscle strength and se therefore have fewer bowel problems than complete injuries.

designs a bowel program specifically for yo

- The level and completeness of you
- Past and present medical problems

April 2014

This factsheet tells you about problems with your vision after a TBI and how to treat them.

> The Traumatic Brain Injury Model Systems Program is sponsored by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education. (See http://www.msktc.or g/tbi/model-systemcenters for more

What you need

- Your vision is Traumatic brail
- Treatment can

What is vision

We often think about vis sense of what we see. thinking and moving. W our daily living activities life. Depending on its lo involved in visual proce involved in vision, occip

How are visio

Many members of your and can check for visio problem. They can mail doctors who diagnose ophthalmologists (op-ti additional training in w identify the most appro-

What are con

There are a variety of most common types of

- Blurred visio
- Double visio Decreased p
- There can also be con

How can thes

Many of the visual pro example.

- Close object
- It may take Printed lette
- It may be di
- It may also be harden Imitable in p
 - Bothered by

Adaptive Sports and Recreation



SCI Fact Sheet

December 2016

This fact sheet explains the important role that adaptive sports and recreation can play after a spinal cord injury (SCI). It also describes different types of sports equipment and points out some health problems to watch for as you participate in sports activities.

If you have an SCI, adaptive sports and recreation may be key to your lifelong wellness. These activities may also help you to engage with your community. Many options are available:

- Outdoor recreation activities (for example, adaptive kayaking, fishing, or snow skiing)
- Performing arts (for example, adaptive dance group)
- Individual sports (for example, wheelchair racing or hand
- Team or competitive sports (for example, wheelchair basketball, wheelchair tennis, quad rugby, or sled hockey)

Even if you have never taken part in sports before, you can find an adaptive activity that is right for you!

Importance of Adaptive Sports and Recreation

An SCI does not have to keep you from being active. Adaptive sports and recreation are good for your health. Without such activity, you may be at higher risk for physical and mental health problems, such as Obesity, heart disease, and depression. You may also feel left out if you do not engage in enjoyable activities. Others may assume that you cannot be active just because of your injury.

Adaptive sports and recreation can help you get past these challenges. People with SCI who are involved in adaptive sports and recreation in the community are more likely to

- hold a steady job.



sponsored by the National Institute on Disability and Rehabilitation Research. Office of Special What is a bowel program Education and A bowel program is a plan to retrain your b Rehabilitative Services, U.S. Department of Education. (See http://www.msktc.org/sci/ model-system-centers to

examination are an important part of this re

- Description and pattern of bowel pr





The Spinal Cord Injury

more information)

Model System is

Infocomics in English and Spanish





Narrated Slideshows

View our slideshow on understanding itchy skin after burn injury, why it occurs, ways to talk about it with your health care team, and strategies for managing it.

To watch the slideshow in full screen mode, click the full screen button located at the far bottom-right corner of the video. Once you click the button, the video will expand so that it covers the majority of your screen.

To exit full screen mode, simply press the Esc button on your keyboard or click the full-screen button again.





Video Products

Home About Spinal Cord Injury Traumatic Brain Injury Burn Injury Knowledge Translation For Grantees

HOME > SCI > HOT TOPICS > BOWEL_FUNCTION > BOWELS CONTROL YOU

Don't Let Your Bowels Control You

Part of the Hot Topics Series: Managing Bowel Function After Spinal Cord Injury



Managing Bowel Function after SCI Videos

Click on the images below to view videos on Managing Bowel Function after SCI



Featured Video: Managing Bowel Function after Spinal Cord Injury

Time 19:46



Mental Challenges of a Spinal

Cord Injury Time: 1:15



Research on the Causes of Constipation

Time: 1:42



Fecal Incontinence

Time: 0:56







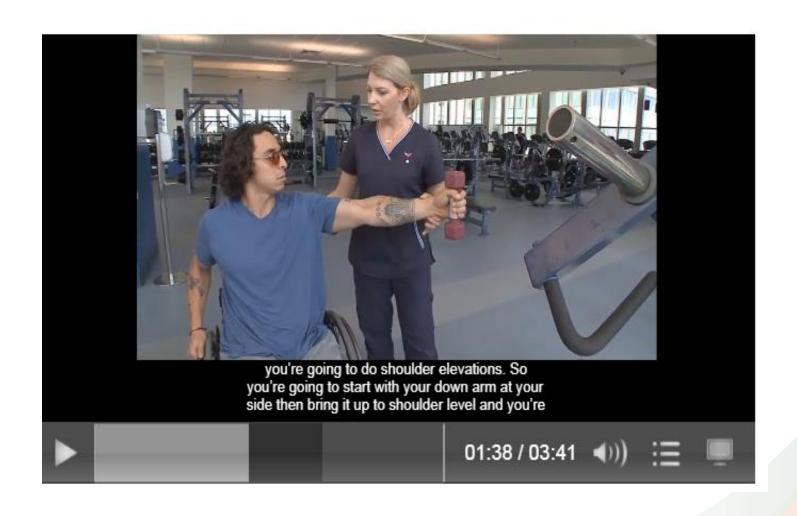


The Brain Injury Family Intervention Feelings Checklist



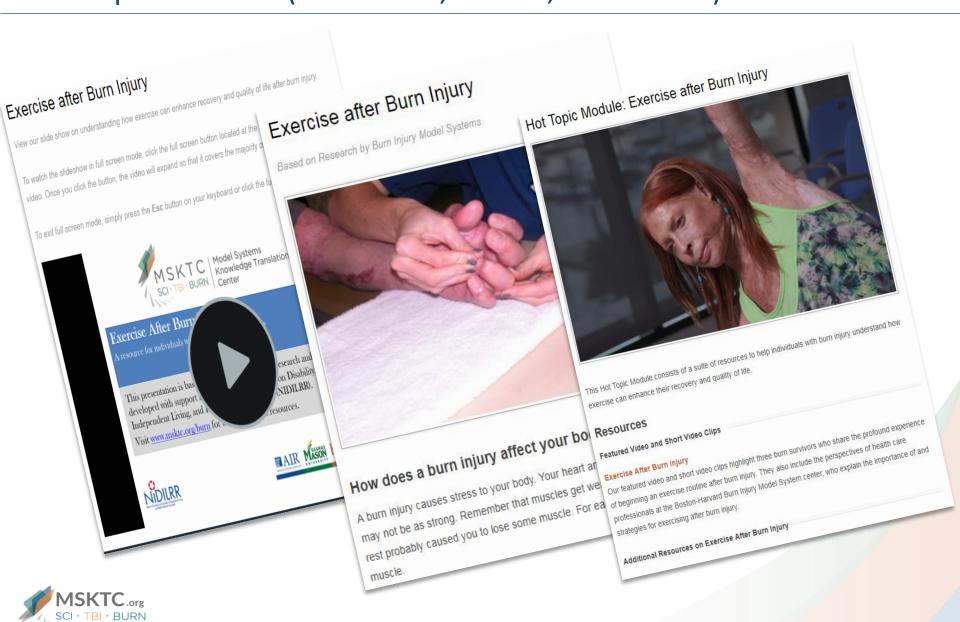


Managing Pain: Shoulder Exercise for People with SCI



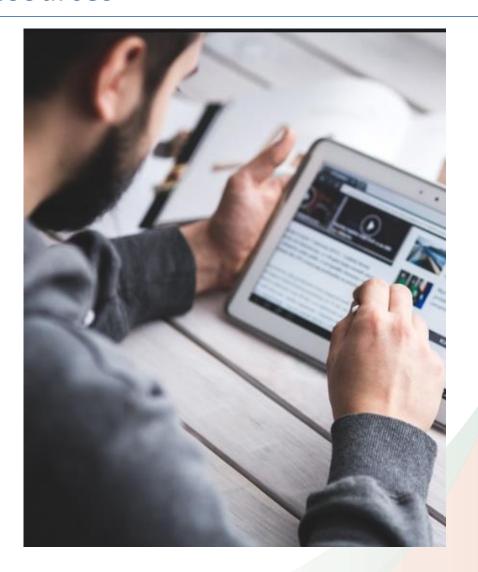


Hot Topic Modules (Factsheets, Videos, Slideshows)



Other Free Research-based Resources

- Facts and figures
- Model System database information
- Systematic reviews
- Publication database
- KT toolkit





Applying KT to Communicate and Develop Health Information Products

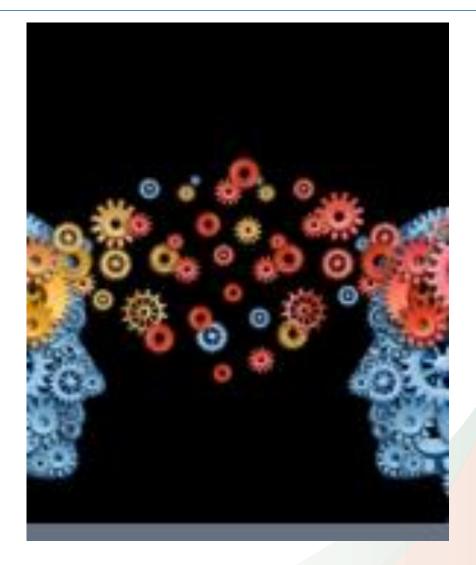
Lessons learned from the MSKTC



Knowledge Translation (KT) Defined

KT is defined as the exchange, synthesis and ethically-sound application of knowledge— within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research . . .

—Canadian Institutes of Health Research





Applying KT in Developing MSKTC Resources

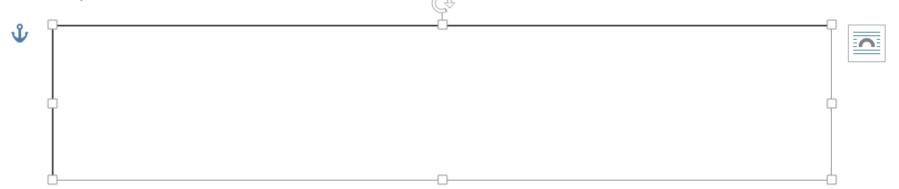
- Understand consumer needs through KT research
- Establish a clear purpose
- Empower and support decision making
- Manage emotional impact
- Use plain language writing
- Have clear organization
- Use images to enhance comprehension
- Conduct consumer testing
- Obtain Model Systems researchers' input and approval
- Translation into Spanish
- User feedback for continuous improvement



Understanding consumer needs to identify topics



- 4. Please let us know other traumatic brain injury topics that you would like to learn about, starting from the topic you are most interested in:
 - 1.
 - 2.
 - 3.
- 5. If you have more than 3 topics in mind, please use the box below for additional topic suggestions and/or comments:





Establish clear purpose

- Writers need to understand why patients and families need a product
- Readers should be able to easily identify the purpose of a health information product and what they can do with the information.





Empower and support decision making

- Include information to help users make decisions or take actions.
- Information should be action-oriented whenever possible, presented in terms of actions taken by a clinician, patient, or family member to address the medical need.
- For example, a factsheet discussing an effect of the injury (such as bowel dysfunction) should focus on the steps taken to manage the effect and reduce its impact rather than focusing on the effects of the injury on normal function.



For most audiences, this rule applies:

Never tell something that I can not do anything about.



Managing emotional impact

Typically, patients and family members do not view information objectively but through an emotional lens.



Strategize around the emotional impact

- Be aware of potential emotional reactions to the amount or nature of information that may affect motivation to continue reading and/or act upon the information provided.
- Recognize and limit "worry-producing" content.
- Present information in a way that increases patient or family member self-efficacy.
 - Include positive coping approaches to outcomes that are outside the control of the patient or family member



Strategize around the emotional impact



Use qualifiers, e.g., "for most people" or "sometimes"



In general, avoid scare tactics because they are not helpful



Unavoidable negative info should be tempered positive coping and encouraging statement



Strategize around the emotional impact: Examples

[function loss or negative outcome] can be embarrassing or making you feel isolated.

However many people have found ways to overcome these feelings

Thinking about possibilities can be frightening. However, being aware of possible problems gives you the chance of avoiding them or act quickly to reduce their impact



Plain language writing: True or False?



Writing in plain language is a federal law.



Plain language is watering down or dumbing down.



Plain language is all about how many words that writers use and how difficult the words are for readers to understand



Plain language writing

- Plain language writing focuses on helping readers quickly:
 - Find what they need
 - Understand what they read
 - Act appropriately on what they understand



Plain language writing guideline



Use medical terminology sparingly only to assist patients in clinical settings



Define and explain physiology, anatomy or complex concept with images and pictures when appropriate



Use everyday words in place of technical jargons



Avoid ethnocentric analogies and metaphors



Use simple sentences and present tense when possible



Have clear organization



What is the topic?



What is the takeaway?



What do the words mean?



What questions does this answer?



Where can I learn more?



Where does this information come from?



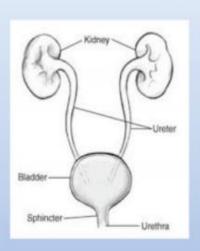
Use images to enhance comprehension

- Anatomical diagrams should show where the anatomy is located in the body by showing the anatomy within an outline of the body
- Anatomical diagrams should be simple and easy to read
- Use labels for only the items that are being discussed in the resources
- Images should be concrete not conceptual
- Avoid using photos evoking negative emotional reaction.
 Use diagram instead

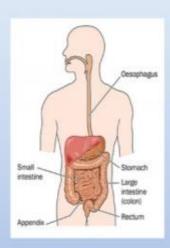


Effective and ineffective graphics

Effective and Ineffective Graphics



Reader doesn't know where anatomy is located.*



Better: Anatomy has physical context



Consumer testing

- Have a clear purpose: Do the resources help make patient decision easier?
- Assess comprehension
- Confirm usefulness
- Determine and manage emotional reaction
- Ensure cultural, gender, ethnical appropriateness
- Obtain feedback for improvement





Quality assurance to ensure quality

Model Systems project directors' review and approval

Source

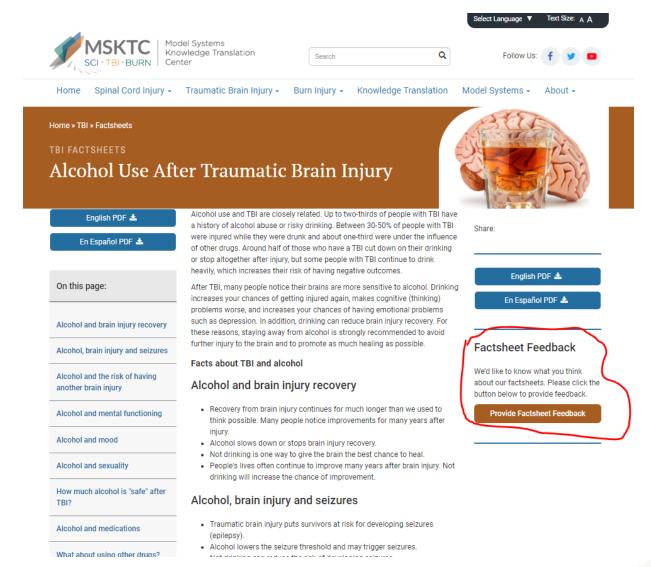
Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the TBI Model System directors.

Source

Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the SCI Model System directors.



User Feedback for Continuous Improvement





Become a MSKTC Ambassador



Become a MSKTC Ambassador

- 1. Use MSKTC resources in your practice
- 2. Share MSKTC resources with patients and families
- 3. Use social media or other channels to share MSKTC resources with your networks
- 4. Contact the MSKTC for media toolkits with sample newsletter messages, social media postings and email templates

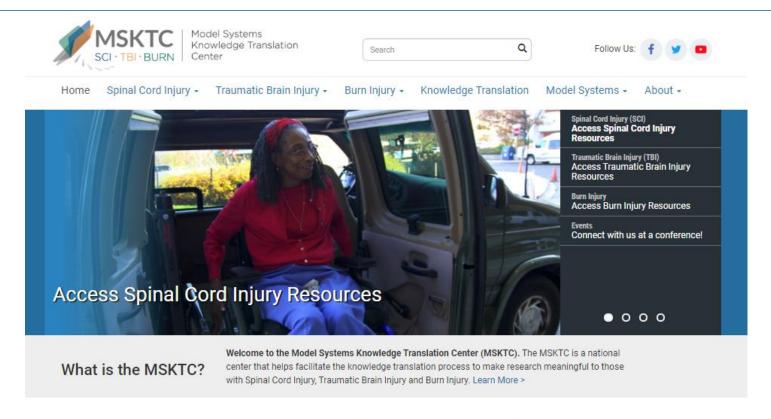


Tour of the MSKTC Website



Tour of the MSKTC Website

www.msktc.org



INJURY TYPE & RESOURCES









Questions?





Contact Information

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Thank you!

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