



# Webinar Series

*United Spinal Association*

**Webinar title:** What rehab is appropriate for SCI and when?

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Institute for Functional Restoration

<http://restorefunction.org/>

The Institute for Functional Restoration has the mission to restore function to people with neurologic disorders by creating a sustainable commercial model for neuromodulation technologies. Founded in 2013, the IFR is a non-profit based at Case Western Reserve University (Cleveland, OH).



[www.NeurotechNetwork.org](http://www.NeurotechNetwork.org)

***Helping people regain life thru neurotechnology***

Focusing on education of and advocacy to access neurotechnology devices, therapies and treatments for people living with impairments, their care-givers and medical professionals.



<https://unitedspinal.org/>

United Spinal Association is dedicated to enhancing the quality of life of people living with spinal cord injuries and disorders (SCI/D).



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# Want to Ask a Question?

Questions

Type question here.

Send



# Disclaimer

*The information presented in this webinar is not meant to replace the advice from a medical professional. You should consult a health care professional familiar with your specific case, concerns and condition.*

*Neurotech Network and its representatives do not endorse, rate, sell, distribute, prescribe, administer or recommend any products, procedures or services. We highly suggest for you to take information to a trained medical professional familiar with your case to discuss options that are best for you.*



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# Webinar Agenda

- What are the components of rehab?
- How to advocate for yourself/your family?
- Preparing for the kick-out
- Rehab doesn't end at discharge
- Reasons for denials that are not valid
- Tips & Tricks for getting what you need
- Resources to learn more





# QUESTION?

Question: Where did you go for your acute (initial) rehab post injury?

Answer choices (pick one):

- Model SCI system
- General rehab hospital (like Healthsouth)
- Nursing home or skilled nursing facility
- Didn't do rehab

# WHAT ARE THE COMPONENTS OF REHAB?



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# Terms to know

Acute Rehabilitation

Subacute Rehabilitation

Home Care

Outpatient Rehabilitation

Nursing Home or Skilled Nursing Facility



# Primary Goals

- Enable you to perform activities of daily living as independently as possible
  - *Ex. Physical therapy to improve strength and balance*
  - *Ex. Assistive equipment demos and trials*
  - *Ex. Establish a bowel and bladder management program*
  - *Ex. Wheelchair use skills*
- Teach you how to cope with barriers in the physical environment
  - *Ex. Navigate public transportation*
  - *Ex. Modify your house*



# Important Points About Securing Appropriate Rehab

- There are many different types of rehabilitation programs offered in different rehabilitation settings.
- The type of program you choose should depend on both your rehabilitation needs *and* your health insurance coverage (not just geographic proximity)
- You may progress through more than one type of rehabilitation program during your recovery.
  - *Advocate aggressively for appropriate SCI rehabilitation (don't take no as a final answer)*
  - *Enlist support from legislative offices and SCI advocates such as United Spinal Association*



# Potential members of your rehab team

- Physical therapist
- Occupational therapist
- Psychiatrist
- Respiratory therapist
- Rehabilitation nurse
- Clinical psychologist
- Dietician
- Alternative therapists
- Urologist
- Chaplain
- Orthotist/Prosthetist
- Rehab technician/DME rep
- Social worker
- Rehabilitation care manager
- Speech-language therapist
- Recreation therapist
- Vocational rehab specialist
- Peer mentor
- Sexuality educator





## STEPS FOR CHOOSING A HIGH-QUALITY REHABILITATION PROGRAM

### STEP 1 YOUR NEEDS

What are your current rehabilitation needs?

- How healthy are you?
- How intense do you need rehabilitation to be?
- How severe is your condition?

### STEP 2 INSURANCE

What kind of health insurance do you have?

Does your health insurance plan limit the amount and type of therapy or other services you can have?

### STEP 3 SETTING

What rehabilitation setting will best suit your needs?

- Acute rehabilitation facility
- Subacute rehabilitation facility
- Day rehabilitation
- Home
- Outpatient
- Nursing Home
- Skilled nursing facility

### STEP 4 QUALITY OUTCOMES

Do the outcomes of programs you are considering reflect high-quality care?

- FIM scores
- Where past patients were discharged to (home, nursing home, or assisted living)
- Patient and family satisfaction
- JCAHO accreditation
- CARF accreditation

Source: Choosing a High-Quality Medical Rehabilitation Program.  
Link to USA Knowledge Book:  
<https://askus-resource-center.unitedspinal.org/index.php?pg=kb.page&id=1509>



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# New Beginning Back Pack Program



# QUESTION?

Question: What are the elements that you received in rehab?

Check all that apply

- Physical therapy
- Occupational therapy
- Recreational therapy
- Nutrition resources
- Psychology/clinical counseling
- Vocational rehab
- Alternative therapy (i.e. massage, acupuncture)
- Peer support
- Speech-language therapy
- Sexuality education
- Bowel and bladder management program

# How to advocate for yourself and/or your family?

- Know and understand your medical condition
- Know your rights – you can appeal denials of reimbursement for services
- Self-Determination – you can control your own life
- Assertive vs Aggressive
  
- Sources:
  - <https://askus-resource-center.unitedspinal.org/index.php?pg=kb.printer.friendly&id=24>
  - <https://www.christopherreeve.org/blog/daily-dose/advocating-for-your-medical-needs>
  - <https://facingdisability.com/resources/advocacy>



# Preparing for the kick-out

- It's going to stir up emotions
- Prepare yourself to develop a new routine, things will be different from the hospital
- Be adaptable, it's OK to try new things, new techniques
- Take it one day at a time
- Talk with other people with SCI/D, you're not alone
- Ask for help if you need it
- Stay active, including through adaptive sports groups





# Preparing for the kick-out

## How did you deal with the transition from hospital to home?

VIEW ALL



## What was the hardest part about coming home?

VIEW ALL



## Do you live independently?

VIEW ALL



- <https://facingdisability.com/spinal-cord-injury-videos/going-home>



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# REHAB ISN'T OVER AFTER DISCHARGE



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**Inpatient & Outpatient  
stays getting shorter...**

**The Human Body  
only heals so fast...**



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# Rehabilitation vs Fitness

- **Definition:** Rehabilitation is a program of interventions designed to facilitate the process of maximizing an individual's ability to live, work, and learn to their highest potential.
- **Focus is**
  - *Restoration/recovery*
  - *Compensation*
  - *Limitations/adjustment*
  - *Independence*
- **Definition:** Fitness is physical activity that is planned, structured, and repetitive for the purpose of conditioning any part of the body.
- **Focus is**
  - *Improve health condition,*
  - *Maintain or improve fitness, and*
  - *Prevention/performance*

*Wellness: An active process of becoming aware of and making choices toward a more successful existence*



# Types of Programs

- Clinical Programs
- Stand Alone Programs
- Public Access & Private Gym Programs



# Clinical Programs

- Locations:
  - *Rehabilitation Facility*
- Gives You Access to:
  - *Trained Rehabilitation Therapists*
- Guidance
  - *Rehabilitation Equipment*
- Program Structure:
  - *Goal-Oriented*
- Financial Commitment:
  - *Typically not covered under insurance. Payment plans available*



# Clinical Program Access to Services





# Examples of Programs

- Beyond Therapy - Atlanta, GA: <http://www.beyond-therapy.org/>
- Brooks Rehab Neuro-Recovery Center - Jacksonville, FL: <https://brooksrehab.org/services/neuro-recovery-center/>
- Neurorecovery Network – Several Locations: <https://www.christopherreeve.org/living-with-paralysis/rehabilitation/neurorecovery-network-and-rehabilitation>
- PEAK Center – Englewood, CO: <https://craighospital.org/programs/the-peak-center>
- Precision Rehabilitation – Long Beach, CA: <http://precisionrehabilitation.com/>
- Courage Kenny Rehabilitation Institute— Minneapolis, MN: <http://www.couragecenter.org/>



# Stand Alone Programs

- Locations:
  - *Specialized Facility*
- Gives You Access to:
  - *Personal Trainers/Exercise Physiologists*
  - *Specialized Equipment*
- Program Structure:
  - *Goal-Oriented & Self-Motivated*
- Financial Commitment:
  - *Membership fees or up-front payment*



# Stand Alone Program Access to Services



■Beyond the Chair – San Antonio, TX:

<http://www.beyondthechair.org>

■Buckeye Wellness Center – Valley View, OH:

<http://www.buckeyewellnesscenter.com>

■C.O.R.E. – Northridge, CA:

<http://www.centerofrestorativeexercise.com>

■CORE FLORIDA – Longwood, FL:

<http://www.coreflorida.com>

■Journey Forward – Canton, MA:

<http://www.journey-forward.org/>

■Mobility Fitness Institute – Tucson, AZ:

[www.mobilityfitnessinstitute.com](http://www.mobilityfitnessinstitute.com)

■NeuAbility – Denver, CO:

<https://neuability.org>

■NeuroFit360- Pembroke Pines, FL:

<http://neurofit360.com/>

■NextSteps Chicago-Willow Springs, IL:

<http://www.nextstepschicago.org>

■Next Step Fitness – Several Locations:

<http://www.nextstepfitness.org>

■Project Walk – Several Locations:

<http://projectwalknj.com>

<https://www.pwboston.com>

<https://www.projectwalkhouston.com>

■Push to Walk- Riverdale, NJ:

<http://www.pushtowalknj.org>

■Pushing Boundaries- Redmond, WA:

<http://pushing-boundaries.org>

■Race to Walk- Mooresville, NC:

<http://racetowalk.org>

■REACT – Dallas, TX:

<http://www.neuroreaction.org>

■SCI-FIT - Sacramento, CA:

<http://www.sci-fit.org/>

■SCI Total Fitness – online:

<http://www.scitotalfitness.com>

■STAR Rehab – Grand Blanc, MI:

<http://www.starrehab.com>

■Stay In Step – Tampa, FL:

<https://stayinstep.org>

■The Recovery Project - Two Locations in MI:

<http://www.therecoveryproject.net/>

■TheraFit Gym, New Lutherville, MD:

<http://www.therafitgym.com>

■Walk The Line – Southfield, MI:

<http://walkthelinetoscirecovery.com/>



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# Public Access/Private Gyms

- Locations:
  - *Gyms, Wellness Centers, Parks, Swimming Pools*
- Gives You Access to:
  - *Limited or No Supervision (self-directed)*
  - *Fitness Equipment*
- Program Structure:
  - *Limited or None*
- Financial Commitment:
  - *Low cost fees or Free*





# Public Access and Private Gyms





# Questions to Ask

- What should I expect from a typical program?
- Is it a rehabilitation program or a fitness program?
- Will there be a trained professional monitoring my program? If so, what are his/her qualifications and what are his/her experiences working with people with SCI?
- What type of equipment will I have access to?
- What is the length of the program?
- How much will this cost me?



# Where to Find These?

- Spinal Cord Injury Resource Center : <https://askus-resource-center.unitedspinal.org/index.php?pg=kb>
- National Center on Health Physical Activity & Disability: <https://www.nchpad.org/Directories>
- Wellness Center/YMCA
- Therapeutic Recreation
- Parks & Recreation
- Shepherd Center App – SCI-Ex



# HOW UNITED SPINAL CAN HELP YOU/UPDATE ON UNITED SPINAL REHAB ADVOCACY



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# Maximizing Rehabilitation Outcomes

- United Spinal Association has the policy and advocacy staff, resource center and chapters/support groups structure in place to ensure people who leave institutional settings have an improved quality of life back in their communities.
- United Spinal Association is leading an education and awareness campaign, entitled Maximizing Rehabilitation Outcomes, to improve rehabilitation outcomes for people living with spinal cord injuries and disorders (SCI/D). United Spinal is working with leading rehabilitation facilities and hospitals across the country including National Institute on Disability, Independent Living and Rehabilitation Research's Model Systems Knowledge Translations Centers.
- The project is four-fold: Education, Expertise, Research, Community Integration.
  - *Writing clear guidelines on policy and available benefits – Medicare, Medicaid etc.*
  - *Preparing rehab education toolkits/guidelines needed for Consumers, Case Managers, Directors of Nursing, Physicians, Clinicians*
  - *Defining criteria for SCI Centers of Excellence to define what SCI, other specialty rehab is, what it should be*
  - *Researching/Collecting Rehab Outcomes and Health Economics data*



# Roadblocks to Rehabilitation

- Lack of rehab reimbursement / Medicaid or Medicare or other insurance
- Eligibility in question: collateral injuries, broken bones, vent weaning or TBI resulting in intervening care in a SNF or long-term facility in lieu of SCI rehab - delaying factor in getting the right rehab therapy
- Pressure ulcer preventing or delaying SCI rehabilitation
- Not initially able to participate in a minimum of 3 hours of therapy
- Transitioning to different levels of rehabilitation (difficult to go back to in-patient level). Continually receive stories about being discharged to home from SNF or LTAC after wound healing without receiving SCI rehab



# Reasons for Denial = Not valid!

Chris is a 43 year-old male, on ventilator, in ICU for 10 months and no rehab prospects due to no appropriate SCI rehab in Maine...

Many hospitals, in Maine and throughout New England: “We are not able to take patients on ventilators” and “We don’t accept Maine Care”.

Conclusion & next steps:

- Enlisted legislative offices, ME Governor's Office and ME Dept of Protection & Advocacy support to demand care that had been denied in ICU
- Orchestrated single-patient Medicaid contract for out-of-state SCI rehab.



# Reasons for Denial = Not Valid!

Sean is a male in his 20s with a cervical injury, from Illinois

He was initially denied rehab reimbursement as his insurer falsely claimed: “He is unlikely to improve so we’re not paying for SCI rehab.”

His parents successfully fought for therapy reimbursement with intervention by United Spinal Information Specialists.

What is the Improvement Standard anyway?



# Tips & Tricks: For getting the rehab you need

- Obtain a copy of the full (not abbreviated or summarized) explanation of insurance benefits. Read your policy carefully and thoroughly.
- Determine the rehabilitation benefits: inquire about the number of allowed days of coverage for inpatient acute and sub-acute rehabilitation, outpatient and home health rehabilitation; is there an annual maximum number of days; is there a lifetime maximum number of days (these need to be differentiated according to the above categories of service).
- Inquire about rehabilitation in a SCI/D-accredited rehabilitation facility; does this include both an in-state or out-of-state facility?





# Tips & Tricks: For getting the rehab you need

- Submit an appeal if you're denied services!
- Realize that insurers will typically only pay for one episode of inpatient rehabilitation so it's important to attend a facility that can provide high quality SCI specific services to maximize your stay.
- Many acute care facilities will not accept patients that have first attended a long term care facility. Before transferring to any facility, be certain that the long term plan is in place and agreed upon by all parties.
- If you are denied out of state services, contact your legislators office(s) and seek support.



# Resources on Our Website

<https://www.unitedspinal.org/ask-us/>

- Seek guidance from our Information Specialists [askus@unitedspinal.org](mailto:askus@unitedspinal.org)
- In the search field, type in 'Rehab guidelines' to find the link to United Spinal Association Guidelines for Selecting a Rehabilitation Facility:  
<https://askus-resource-center.unitedspinal.org/index.php?pg=kb.page&id=1717>
- In the search field, type in 'Rehabilitation, New Injury & Recovery Programs' to find the link to United Spinal Association's Rehabilitation Knowledge Book:  
<https://askus-resource-center.unitedspinal.org/index.php?pg=kb.book&id=11>
- Find your Members of Congress: <https://unitedspinal.org/advocacy-action/resources/>



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