CHRISTOPHER & DANA REEVE FOUNDATION
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Pediatric Spinal Cord Injury

Spinal cord injury in children can feel especially challenging for families. But whether caused by trauma or a medical condition, paralysis need not limit a child's life. Understanding what to expect in the early days after diagnosis can help parents and caregivers begin mapping a path toward recovery and a new normal.

Q: What is the incidence and prevalence of pediatric spinal cord injury?

Spinal cord injury in individuals under the age of 20 occurs at a much lower rate than injury in the adult population, accounting for roughly 20% of all traumatic injuries each year. Children under the age of 15 sustain between 2% - 5 % of these injuries, while about 14% - 18% of injuries occur in those 16-20 years old. Teenage boys face the highest incidence. A top cause of injury in children and adolescents is car

accidents, but other traumatic events such as falls, sports injuries, gun violence, and damage to the cervical region of the spine during birth can also result in injury. Non-traumatic causes of pediatric spinal cord injury include medical conditions such as acute flaccid myelitis, a rare neurological disorder that affects the nervous system; spina bifida, a neural tube birth defect that results in an incomplete closure of the spinal column; and transverse myelitis, an inflammation of the spinal cord.

Q: How is pediatric spinal cord injury diagnosed?

A physical examination will be conducted to assess symptoms and identify lost function and/or sensation. Computed tomography (CT) scans and magnetic resonance imaging (MRI) will be used to identify bone, organ, or tissue damage caused by injury.

Children or adolescents who have been in car accidents, or sustained injuries during sporting events, in falls, or through activities such as diving or trampolining, should always be assessed for spinal cord injuries. Signs of injury can include spinal pain, weakness or lost sensation in the hands and feet, irregular blood pressure, sweating, shivering, gastrointestinal dysfunction, and incontinence.

Extra care is needed in diagnosing pediatric spinal cord injury. For some injuries that stretch or affect the child's spinal cord but do not fracture vertebrae, abnormalities may not appear on diagnostic images. Known as "spinal cord injury without radiographic abnormality" (SCIWORA,) this may occur in less severe injuries or sports-related trauma. Additionally, about 25% of children with spinal cord injuries experience a delay in the onset of symptoms ranging from 30 minutes to four days after injury, making diagnosis more difficult.

Q: What treatments should families expect?

Treatment will depend on the level and severity of the injury. Steroids might be given immediately after injury to reduce swelling around the cord. Surgery may also be needed to relieve pressure and/or stabilize the spinal column. For injuries in the cervical region, a mechanical ventilator may be needed to help the child breathe. Following initial care, long term rehabilitation will require occupational and physical therapy centered around regaining as much function and independence as possible.

Q: What specialists will be part of our child's medical team?

An interdisciplinary team of healthcare providers will work with families to treat the many physical and emotional disruptions caused by spinal cord injuries. A physiatrist – a doctor who treats conditions that affect the function of the brain, spine, bones, or joints and focuses on rehabilitation – may oversee care. Other team members will likely include a physical therapist who focuses on strengthening mobility and coordination; an occupational therapist who will help the child relearn daily tasks

such as getting dressed, bathing, and eating; a speech language pathologist for swallowing issues, and a social worker to help parents and caregivers navigate insurance policies, support services, and the transition back to the home.

Q: Are there any complications or secondary conditions that specifically affect children living with spinal cord injuries?

Scoliosis, an abnormal curving of the spine, occurs in many children who are injured before they have reached the age of puberty. Limited bladder capacity may cause incontinence for children injured at an early age and controlling bladder function for urinary incontinence or an ability to empty the bladder will provide good bladder health into adulthood. And while depression can affect both children and adolescents, teenagers may be especially at risk as they struggle with an increased dependency on others at a developmental age when they are ready for independence.

Q: Are there clinical trials specific to pediatric spinal cord injury?

Yes. Clinical trials related to spinal cord injury in the pediatric population may be found through a database maintained by the U.S. National Library of Medicine at www.ClinicalTrials.gov.

Q: Which hospitals and rehabilitation centers specialize in pediatric spinal cord injury?

Major children's hospitals will have dedicated rehabilitation programs for children with spinal cord injuries. Specialized rehabilitation programs for adolescents can be found at medical centers with comprehensive spinal cord injury treatment programs such as the Shepherd Center in Atlanta, GA and Craig Hospital in Englewood, CO. Many adult rehabilitation centers also accept teens, but treatment should be tailored to the specific physical and developmental needs of this age group. There are three Shriners hospitals that specialize in spinal cord injury located in Philadelphia, Chicago and Sacramento.

Q: How should I chose a rehabilitation facility for my child?

Choose a long-term rehabilitation facility by researching its experience with pediatric spinal cord injury. What child and adolescent-centric resources and family supports define the program? Is family housing available near the hospital? Are there tutors or an onsite school program for children and teens to continue their education as they recover? For teens who benefit from being with peers, determine how many adolescents are typically admitted to the program each year. Ask to speak with other families whose children are or have previously been patients at the facility.

The Reeve Foundation's National Paralysis Resource Center has produced a joint booklet with Shepherd Center "Restoring Hope: Preparing for Rehabilitation After Spinal Cord Injury" which includes some checklists of questions to consider when

choosing a rehabilitation facility. It can be viewed at https://s3.amazonaws.com/reeve-assets-production/Restoring-Hope-Booklet-FINAL-4-20-20.pdf or call 800-539-7309 to ask an Information Specialist for a free print copy.

Q: What resources are available for families and children living with spinal cord injuries?

Support groups can help injured children and adolescents and their families adjust to new challenges and successfully pursue engaged and active lives. Check with medical teams to see what is available at your hospital or rehabilitation facility. The National Paralysis Resource Center (NPRC) can help connect families with local resources and Information Specialists comprehensively answer any questions about living with paralysis, from how to navigate Medicaid to adapting a home around a new injury. The NPRC's monthly webinars with Nurse Linda also provide regular tips on managing health while living with paralysis. Nurse Linda writes a weekly blog for the paralysis community which ends with pediatric considerations, she also devotes an entire blog to pediatric issues once a month. Nurse Linda's blogs may be read here: https://www.christopherreeve.org/blog/author/NurseLinda. Families may also download the Reeve Foundation's free wallet cards which provide information to aid medical professionals in case of emergency such as autonomic dysreflexia, a life-threatening condition caused by a dangerous increase in blood pressure. A pediatric version of the autonomic dysreflexia card can be found at: https://s3.amazonaws.com/reeve-assets-production/AD-Guide-Ped-5-18.pdf.

Information for caregivers can be found in the Paralysis Resource Guide (www.ChristopherReeve.org/Guide) and in the Reeve Foundation's factsheet on caregiving (https://s3.amazonaws.com/reeve-assets-production/Caregivers-PCAs-Respite-2-21-1.pdf). . The Reeve Foundation has a peer mentoring program called the Peer & Family Support Program (PFSP). The PFSP offers **caregiver to caregiver mentoring** (www.ChristopherReeve.org/peer) as well as **virtual support groups for caregivers** (https://www.christopherreeve.org/get-support/reeve-foundation-virtual-support-group).

Sources: Model Systems Knowledge Translation Center, Merck Manual, Stanford Children's Health, Northwest Regional Spinal Cord Injury System at the University of Washington, C.S. Mott Children's Hospital at the University of Michigan, Centers for Disease Control and Prevention.

Need to talk to someone?
Our Information Specialists are available to answer your questions.
Call toll-free 1-800-539-7309 Mon-Fri, 9 am-8 pm EST.
Schedule a call or ask a question online at https://www.ChristopherReeve.org/Ask

Resources for Pediatric Spinal Cord Injuries:

Alfred I. duPont Hospital for Children at Nemours
https://www.spinalcord.com/alfred-i.-dupont-hospital-for-children-at-nemours
https://www.nemours.org/locations/wilmington-ai-dupont-childrens-hospital.html
1600 Rockland Rd.
Wilmington, DE 19803

American Academy of Physical Medicine and Rehabilitation (AAPMR)
http://www.aapmr.org
9700 West Bryn Mawr Ave, Ste 200
Rosemont, IL 60018-5701
Phone: 847-737-6000
Email: info@aapmr.org
The patients & family section of AAPMR's website includes information on physiatrists and common disorders treated by physiatrists, as well as a searchable database of physiatrists. To find a physiatrist, please use their locator tool:
https://members.aapmr.org/AAPMR/AAPMR_FINDER.aspx
Physiatrists are physicians who specialize in physical medicine and rehabilitation. They may specialize in certain areas such as **pediatrics**, spinal cord medicine, and sports medicine.

American Spinal Injury Association (ASIA): Facts on Pediatric Spinal Cord Injury
http://asia-spinalinjury.org/committees/pediatric/pediatric-committee-news-and-resources/pediatric-spinal-cord-injury-facts/

CareCure's article on Pediatric Spinal Cord Injury by Wise Young
http://carecure.org/index.php?page=viewarticle&afile=8_May_2003@PediatricSCI.htm
This May 2003 article reviews the literature review on emergency care, acute complications, chronic complications, and functional recovery in children with spinal cord injury.

Commission on Accreditation of Rehabilitation Facilities (CARF)
www.carf.org

CARF Accredited Pediatric Rehab Programs (in-patient/out-patient):

Children's Healthcare of Atlanta at Scottish Rite, Atlanta, GA
https://www.carf.org/providerProfile.aspx?cid=19999
Kennedy Krieger Children's Hospital, Inc., Baltimore, MD
https://www.carf.org/providerProfile.aspx?cid=9985
Madonna Rehabilitation Hospital Lincoln, Lincoln, NE
https://www.carf.org/providerProfile.aspx?cid=8241

Christopher & Dana Reeve Foundation: Autonomic Dysreflexia wallet cards for children
www.ChristopherReeve.org/adcard
Please see our free AD wallet cards for adults and children. The children's version has a

light blue cover and has different medication levels than the adult edition. You may download a copy or order a laminated version from the Reeve Foundation. The order form is online at the above link or you may call us at 1-800-539-7309 x7224. Feel free to share the info on the card with your medical team as it was developed with the help of physicians at the Kennedy Krieger Institute. Children with spinal cord injuries above the T6 level are at risk of autonomic dysreflexia.

Christopher & Dana Reeve Foundation: Pediatric NeuroRecovery (NRN) Centers
https://www.christopherreeve.org/research/our-rehabilitation-network/nrn-clinical-centers
The Reeve Foundation sponsors the NeuroRecovery Network at two pediatric centers which offer intensive activity-based therapies to promote functional recovery and improved health and well-being for children living with paralysis.

- Frazier Rehab Institute, Pediatric Rehabilitation, Louisville, KY Email: Miranda Garvin, MirandaGarvin@kentuckyonehealth.org
- Children's Hospital of Pittsburgh of UPMC, Pittsburgh, PA Email: Meg Stranger, Meg.Stanger@chp.edu
- St. Mary's Healthcare System for Children, Bayside NY https://www.stmaryskids.org Phone: 718-281-8987

C.S. Mott Children's Hospital: Living with a Spinal Cord Injury
https://www.mottchildren.org/health-library/ug2580#ug2581

Facing Disability: Pediatric Spinal Cord Injury 101
https://facingdisability.com/spinal-cord-injury/pediatric
http://www.facingdisability.com/expert-topics/pediatric-spinal-cord-injury-101

Gillette Children's Specialty Healthcare: Spinal Cord Injury Program
http://www.gillettechildrens.org/conditions-and-care/spinal-cord-injury-and-related-neurotrauma/
Information on spinal cord injuries from Gillette Children's, a hospital located in Minnesota. The page includes an interactive map of the spinal cord.

International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute
www.spinalcordrecovery.org
707 North Broadway
Baltimore, MD 21205
Phone: 443-923-9222, Toll-free: 800-873-3377
Email: info.sci@spinalcordrecovery.org
The International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute was founded on the philosophy that individuals with paralysis can always hope for recovery of sensation, function, mobility, and independence, months and even years after injury. To maximize on this potential for recovery, ICSCI offers an intense, medically-supervised therapy program with a unique focus on Activity-Based Restorative Therapy. ICSCI was one of the first facilities in the world to combine innovative research

with a unique therapeutic focus on restoration and rehabilitation for both children and adults with acute and chronic spinal cord injuries and disorders, including individuals who require the use of a ventilator. They offer an inpatient program for individuals under the age of 22, outpatient programs for all ages, and have been accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). Most insurance plans are accepted.

Kosair Charities Center for Pediatric NeuroRecovery
http://victoryoverparalysis.org/pediatrics-about-us/
University of Louisville
220 Abraham Flexner Way, Suite 1500
Louisville, KY 40202
Phone: 502-582-7443
Email: kidskickparalysis@louisville.edu
The Kosair Charities Center for Pediatric NeuroRecovery provides activity-based therapies to promote recovery from neurologic injury in children; conducts research to enhance recovery; and trains families, practitioners and scientists to maximize recovery and improve the quality of life for children and their families.

Merck Manual: Spinal Cord Injury in Children
https://www.merckmanuals.com/professional/injuries-poisoning/spinal-trauma/spinal-cord-injury-in-children

Model Systems Knowledge Translation Center: Living with Spinal Cord Injury
https://msktc.org/sci

Shriners Hospitals for Children: Spinal Cord Injury
https://www.shrinershospitalsforchildren.org/shc/spinal-cord-injury
Information on rehabilitation for spinal cord injuries from Shriners Hospitals. There are three Shriners hospitals that specialize in spinal cord injury located in Philadelphia, Chicago and Sacramento.

Stanford Children's Health: Acute SCI in Children
https://www.stanfordchildrens.org/en/topic/default?id=acute-spinal-cord-injury-in-children-90-P02590

University of Washington Northwest Regional Spinal Cord Injury System: SCI in Children and Teens
https://sci.washington.edu/info/newsletters/articles/05win_children.asp#common

For healthcare professionals:

SCI in the Pediatric Population: A Systematic Review of the Literature
Published in J Neurotrauma. Aug 2011; 28(8): 1515–1524.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3143390/

This fact sheet is for the adult who wants to find out more about pediatric

SCI. For materials about SCI at children's reading levels, please ask for our fact sheet called Children and Teen Books & Videos.

This publication is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $10,000,000 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.