

# Spinal Cord Injury in Children and Youth: The Basics

*A list of internet resources to help you learn more about spinal cord injury in children and youth*

Provided by the *Children & Youth Subcommittee* of the  
Brain & Spinal Injury Trust Fund Commission

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Want to learn more about spinal cord injury (SCI) and how it affects children and youth?

Haven't got a lot of time?

We make it easy for you. We've compiled a list of some of the best resources that can give you a basic education about SCI and kids.

We've organized the resources according to five categories:

- For Children and Teens
- For Parents and Families
- For Teachers
- For Other Professionals
- For Policy Makers
- Prevention of SCI in children and youth

Still have questions? Contact us at: [bsitf-info@dhr.state.ga.us](mailto:bsitf-info@dhr.state.ga.us) or 404/651-5112.

*Note: The websites and resources listed here are provided to assist you in learning more about spinal cord injury in children and youth. Their inclusion in the list does not constitute an endorsement of the website or resource on the part of the Brain & Spinal Injury Trust Fund Commission. The content of the websites and resources is the sole responsibility of its owners and authors. Any problems or questions regarding the content should be directed to the appropriate owner and/or author.*

*Updated: June 9, 2009*

## For Children and Teens

### **Think First**

[www.thinkfirst.org/home.asp](http://www.thinkfirst.org/home.asp)

The ThinkFirst National Injury Prevention Foundation offers a research-validated multi-level educational program that has reached over 8 million young people nationally and internationally. ThinkFirst programs educate young people about their personal vulnerability and the importance of making safe choices. The message is: You can have a fun-filled, exciting life, without hurting yourself if you "ThinkFirst." ThinkFirst has chapters throughout the United States and in other countries.

#### Features:

- Separate resource pages for kids, youth, and teens
- Fact sheets and prevention tips
- Links to local chapters for speakers
- Order form for educational products

### **Ability Online**

[www.ablelink.org/public/new/about\\_us.html](http://www.ablelink.org/public/new/about_us.html)

Ability Online is a free internet community where children and youth with disabilities can meet and chat with each other in "a virtual world that transcends boundaries and barriers." It provides many benefits to parents, family members and others who want to make a difference in enabling and enriching the lives of those they know and love.

#### Features:

- Under "About Us/FAQ"
  - Learn more about Ability Online and how to use it
- Under "Registration"
  - Register to become a member of Ability Online

### **Spinal Injuries Association**

[www.spinal.co.uk](http://www.spinal.co.uk)

The Spinal Injuries Association is a British non-profit organization for people with spinal cord injuries.

#### Features:

- Under "SCI Community/Young People"
  - "What's Your Story" – read other people's stories or tell your own
  - "Wha'ever" – book (available in PDF) about a young person with SCI
  - "Have Your Say" – post on a message board
  - "Where Else?" – links to other websites

### **Crip College**

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

Crip College is a web site developed by a young man named Christian Bagg, who has an SCI. He developed the web site to share ideas about wheelchair technology and life in a chair.

Features:

- “Innovating the Wheelchair” and “The Next Step”
  - Provide input about the ideal wheelchair to Christian as he designs new technology
- “Speaking Out” – Christian’s blog
- “Message Board” – post questions, ideas, and observations
- “Tricks of the Trade” – Christian demonstrates how to do things such as go down stairs or get up on curbs in a wheelchair
- “Weblinks” – links to other web sites for people with SCI

### **Spinal Cord Injury Information Network**

<http://www.spinalcord.uab.edu/show.asp?durki=19679>

The Spinal Cord Injury Information Network is a program of the University of Alabama at Birmingham.

Features:

- Under “Search”
  - Type “Speedway Sam” in the search box AND click on “Keywords (Full-text)” just below the search box. Then click on “Pediatric SCI.” Towards the bottom of the page there will be a link to a PDF of “Speedway Sam,” a book about SCI written from the perspective of an eight year old.

### **Safe Kids USA**

[www.usa.safekids.org](http://www.usa.safekids.org)

Safe Kids USA is a member of Safe Kids Worldwide, a global network of organizations whose mission is to prevent accidental childhood injury, a leading killer of children 14 and under. More than 450 coalitions in 16 countries bring together health and safety experts, educators, corporations, foundations, governments and volunteers to educate and protect families.

Features:

- Under “Activities for Kids”
  - Coloring sheets, puzzles and more (free downloads)

Additional Resources

#### **You Tube: “How to Transfer Into a Car”**

[www.youtube.com/watch?v=B9vCpVSCo8s&feature=channel\\_page](http://www.youtube.com/watch?v=B9vCpVSCo8s&feature=channel_page)

#### **You Tube: “Back in Life”**

[http://www.youtube.com/watch?v=rQ0TZ6cxMZM&feature=channel\\_page](http://www.youtube.com/watch?v=rQ0TZ6cxMZM&feature=channel_page)

## For Parents and Families

### **Spinal Cord Central**

<http://helpdesk.spinalcordcentral.org/>

Spinal Cord Central is a program of the United Spinal Association and National Spinal Cord Injury Association. The website was developed to provide information and resources about SCI.

#### Features:

- Under “Home”
  - “Knowledge Books” – a wide variety of resources of SCI
  - “Most Useful” – a ranking of the most searched topics, updated daily
  - “What is PIC?” – an interactive web page that allows you to ask questions of the Spinal Cord Central staff
- Under “Ask Spinal Cord Central”
  - Submit requests for information and resources on any aspect of SCI and receive a response from the Spinal Cord Central staff
- On left-hand side menu bar
  - Training and information on a wide variety of topics including:
    - Adaptive Sports and Recreation
    - Housing (go to “Locating Accessible Housing”)
    - Home Modifications
    - Employment
    - Adaptive Vehicles and Driver Training
    - Caregivers
    - Rehabilitation (including “Choosing a Rehab Setting”)

### **Northwest Region Spinal Cord Injury System**

<http://sci.washington.edu/>

The Northwest Region Spinal Cord Injury System is a program of the University of Washington. The System specializes in care and treatment of people with SCI as well as research on SCI.

#### Features:

- Under “Information and Education”
  - “SCI Pamphlet Series: Staying Healthy After SCI”
  - “Videos for Online Viewing”
    - “Conversations About Living with SCI”
    - “Personal Caregivers”
    - Many other topics

### **Paralyzed Veterans of America**

[www.pva.org/site/News2?page=NewsArticle&id=10811](http://www.pva.org/site/News2?page=NewsArticle&id=10811)

Paralyzed Veterans of America is an organization dedicated to assisting veterans with spinal cord injuries or diseases.

#### Features:

- “Yes, You Can! A Guide to Self-Care for Persons with SCI” – the PVA’s most popular publication provides helpful information about life with a spinal cord injury.

### **Parent to Parent of Georgia**

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

Parent to Parent of Georgia provides support and information to parents of children with disabilities. Their resources include a database of over 4,500 resources, emotional support, reading material, support groups, Early Intervention Programs, and conferences and other special events.

#### Features:

- “Roadmap to Services:” an extensive web-based list of resources for families of children with disabilities
- “Support:” information to receive free telephone peer support (for parents who live in Georgia)
- “Information:” a comprehensive database of over 4,000 resources
- “Education:” Parent Training Information Center

### **Parent Advocacy Center for Educational Rights (PACER) Center**

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

The PACER Center is a Minnesota non-profit organization that was created by parents of children and youth with disabilities to help other parents and families facing similar challenges. PACER provides assistance to individual families, workshops, materials for parents and professionals, and leadership in securing a free and appropriate public education for all children.

#### Features:

- Under “Programs and Resources/Publications:”
  - Articles and brochures on a wide variety of topics
- Under “Programs and Resources/Archived Webinars:”
  - Note: to access these webinars you must first take the brief webinar training provided on the website. These webinars are long, however, they provide great in-depth information.
  - “Resolving Disagreements Through the Special Education Process”
  - “The House of IDEA: Blueprint for a Strong Education Program”

### **National Dissemination Center of Children with Disabilities**

<http://www.nichcy.org/educatechildren/supports/Pages/default.aspx>

The National Dissemination Center of Children with Disabilities uses funding from the U.S. Department of Education to provide information on children and youth with disabilities, including information about education services, laws and practices.

#### Features:

- Under “Families and Community”
  - “Finding Services for Children and Youth”
  - “Understanding the Laws”
  - “Especially for Families”

- Under “Educate Children (3 – 22)” (on left-side menu bar)
  - “Q&A Series on IDEA”
  - “All About the IEP”
  - “Supports, Modifications, and Accommodations for Students”
  - “Resolving Disputes Between Parents and Schools”

**“Going Back to School: A Guide for Recently Injured Teens”**

<http://www.shepherd.org/files/No%20obstacles.pdf>

This publication, produced by Shepherd Center, provides practical advice for students, parents, teachers about how to support a student with SCI who is returning to school.

Additional Resources

**Ability Magazine**

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

**Able Play**

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

## For Teachers

### **Spinal Cord Injury Information Network**

<http://www.spinalcord.uab.edu/show.asp?durki=19679>

The Spinal Cord Injury Information Network is a program of the University of Alabama at Birmingham.

#### Features:

- Under “Psychosocial” (on left-side menu bar)
  - Under “Education & Employment/Education”
    - Links to various sites on SCI, including several that address young people with SCI entering college
- Under “Search”
  - Type “Speedway Sam” in the search box AND click on “Keywords (Full-text)” just below the search box. Then click on “Pediatric SCI.” Towards the bottom of the page there will be a link to a PDF of “Speedway Sam,” a book about SCI written from the perspective of an eight year old.

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#### Features:

- Under “Schools and Administrators”
  - “Specifics of IDEA”
  - “Especially for Teachers”
  - “Professional Development”
  - “Research in Education”
  - “Technical Assistance”
- Under “Educate Children (3 – 22)” (on left-side menu bar)
  - “Q&A Series on IDEA”
  - “All About the IEP”
  - “Supports, Modifications, and Accommodations for Students”
  - “Effective Practices in the Classroom and School”
  - “Resolving Disputes Between Parents and Schools”
  - “Transition to Adulthood”

### **Inclusive Strategies for Teachers**

<http://www.specialed.us/>

This website is for the Calumet County Children with Disabilities Education Board of Wisconsin. It provides valuable information on the education of children with disabilities.

#### Features:

- Under “Issues and Memos”

- Under “Inclusive Education”
  - Practical suggestions for providing accommodations for students compiled from various internet resources

### **Concord SEPAC**

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

The Concord Special Education Parents Advisory Committee is a system wide volunteer organization in Concord, Massachusetts. Its website provides a variety of information and resources on the education of children with disabilities.

Features:

- Under “IEP” (on the left-side menu bar)
  - Under “Accommodations”
    - Legal definitions of accommodations and examples of classroom use
- Under “Other Student Documentation” (on the left-side menu bar)
  - Under “504”
    - Explanation of Section 504 and its implications for students with disabilities

### **Center for Assistive Technology and Environmental Access**

<http://www.catea.gatech.edu/scitrain/>

The Center for Assistive Technology and Environmental Access, a program of Georgia Institute of Technology, is a multidisciplinary engineering and design research center dedicated to enhancing the health, activity and participation of people with functional limitations through the application of assistive and universally designed technologies in real world environments, products and devices.

Features:

- Under “Accommodations” (on the left-side menu bar)
  - Under “Classroom”
    - Under “Motor Impairment” – a list of assistive technology strategies and solutions to address a range of motor impairment issues in the classroom

Additional Resources:

#### **American Association of Spinal Injury Nurses**

[www.aascin.org/sci-nursing-online](http://www.aascin.org/sci-nursing-online)

#### **Planting the Seeds of Partnership: Parents as Instructors in Teacher Education**

[www.Eparent.com/main\\_channels\\_education/Planting\\_Seeds.asp](http://www.Eparent.com/main_channels_education/Planting_Seeds.asp)

#### **The Family Center on Technology & Disability**

[www.fctd.info/show/glossary](http://www.fctd.info/show/glossary)

#### **National Institute of Neurological Disorders & Stroke**

[www.ninds.nih.gov/index.htm](http://www.ninds.nih.gov/index.htm)

#### **National Rehabilitation Information Center**



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

**Sevier County Special Education**

[www.slc.sevier.org/miscdata.htm](http://www.slc.sevier.org/miscdata.htm)

**Georgia Project for Assistive Technology**

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

**Shepherd Center Assistive Technology**

[www.shepherd.org/patcare/spec/tech.asp](http://www.shepherd.org/patcare/spec/tech.asp)

**Children's Healthcare of Atlanta Assistive Technology**

[www.choa.org/default.aspx?id=1842](http://www.choa.org/default.aspx?id=1842)

## For Professionals

### **Spinal Cord Injury Information Network**

<http://www.spinalcord.uab.edu/show.asp?durki=19679>

The Spinal Cord Injury Information Network is a program of the University of Alabama at Birmingham.

#### Features:

- Under “SCI Topics” (on left-side menu bar)
  - A wide variety of topics about SCI

### **National Spinal Cord Injury Association**

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

Founded in 1948, the National Spinal Cord Injury Association is the nation's oldest and largest civilian organization dedicated to improving the quality of life for hundreds of thousands of Americans living with the results of spinal cord injury and disease (SCI/D) and their families.

#### Features:

- Under “News and Info/Fact Sheets”
  - “Educating Nursing Staff to Care for the Spinal Cord Injury Patient”
  - “Pediatric Spinal Cord Injury: Information and Resources”
  - “Autonomic Dysreflexia”
  - “Pressure Sores”
  - “Skin Care”

### **Able Data**

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

Able Data is a project of the National Institute on Disability and Rehabilitation Research and is designed to provide information and resources on assistive technology.

#### Features:

- Under “Products”
  - Provides an extensive list of assistive technology devices organized by purpose
- Under “Resources”
  - Under “Information Centers”
    - Provides an extensive list of internet resources on a wide variety of topics
- Under “Library”
  - Under “Able Data’s Publications”
    - List of fact sheets on assistive technology

### **Neurosurgery: On Call**

[www.neurosurgery.org/sections/section.aspx?Section=PD&Page=ped\\_spine.asp](http://www.neurosurgery.org/sections/section.aspx?Section=PD&Page=ped_spine.asp)

Neurosurgery: On Call is a website developed by the American Association of Neurological Surgeons.

Features:

- Journal article on pediatric spinal trauma

### **Spinal Net**

[www.spinalnet.co.uk/](http://www.spinalnet.co.uk/)

Spinal Net is a website developed by Coloplast, an international health care company. The web site is designed to provide information for people with SCI, their families and caregivers.

Features:

- Under “SCI Explained” (on left-side menu bar)
  - “What is SCI?” - Information, including visuals, on the brain, spinal cord, and nervous system
  - “Causes of SCI”
  - “Effects of SCI”
  - “Management and complications”
  - “Glossary”

Additional Resources

### **Spinal Cord Injury Rehabilitation Evidence**

[www.icord.org/scire/home.php](http://www.icord.org/scire/home.php)

### **Brain & Spinal Injury Trust Fund Commission of Georgia**

[www.bsitf.state.ga.us](http://www.bsitf.state.ga.us)

### **Parent to Parent of Georgia**

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

### **Paralyzed Veterans of America**

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

## For Policy Makers

### **Centers for Disease Control and Prevention**

<http://www.cdc.gov/ncipc/factsheets/scifacts.htm>

The Centers for Disease Control and Prevention (CDC) is a federal agency that monitors health issues, addresses health problems, develops public policy, and promotes prevention for the United States. It provides information for public health professionals, practitioners, lawmakers, researchers, and families.

#### Features:

- “Spinal Cord Injury: Fact Sheet”
- Under “CDC Activities” (left-side menu bar)
  - A listing of the CDC’s current research initiatives on SCI
- Follow: <http://www.cdc.gov/hrqol/pubs/injuries/spinalcord.htm>
  - A listing of the CDC’s articles on SCI

### **Safe Kids USA**

[www.usa.safekids.org](http://www.usa.safekids.org)

Safe Kids USA is a member of Safe Kids Worldwide, a global network of organizations whose mission is to prevent accidental childhood injury, a leading killer of children 14 and under. More than 450 coalitions in 16 countries bring together health and safety experts, educators, corporations, foundations, governments and volunteers to educate and protect families.

#### Features:

- Under “Research/Injury Facts Sheets with Data Sources”
  - Fact sheets on a wide variety of prevention topics (free downloads)
- Under “Research/Reports”
  - Reports on a variety of topics including drowning, pedestrian safety, helmet use, etc. (free downloads)
- Under “Public Policy”
  - “Safe Kids Comments on Federal Legislation”
  - “Congressional Testimony”
  - “Regulatory Comments”

### **Children’s Safety Network**

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

The Children's Safety Network (CSN) is a national resource center for the prevention of childhood injuries and violence. It is designed to assist states in building their capacity to prevent injuries and violence against children.

#### Features:

- Under “State Capacity Building/Policy, Regulation & Legislation”
  - CSN Publication: “Finding Funding for Injury and Violence Prevention”
  - Useful Publications: “NCSL Legisbrief: Preventable Injuries Burden State Budgets”

# Prevention of SCI in Children and Youth

## **Safe Kids USA**

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Safe Kids USA is a member of Safe Kids Worldwide, a global network of organizations whose mission is to prevent accidental childhood injury, a leading killer of children 14 and under. More than 450 coalitions in 16 countries bring together health and safety experts, educators, corporations, foundations, governments and volunteers to educate and protect families.

### Features:

- Under “Research/Injury Facts Sheets with Data Sources”
  - Fact sheets on a wide variety of prevention topics (free downloads)
- Under “Safety Tips”
  - “Safety Information for Parents:” a listing of many prevention topics
  - “Campaigns and Initiatives:” a listing of programs that address car, fire, pedestrian, and toy safety
- Under “Activities for Kids”
  - Coloring sheets, puzzles and more (free downloads)

## **Think First**

[www.thinkfirst.org/home.asp](http://www.thinkfirst.org/home.asp)

The ThinkFirst National Injury Prevention Foundation offers a research-validated multi-level educational program that has reached over 8 million young people nationally and internationally. ThinkFirst programs educate young people about their personal vulnerability and the importance of making safe choices. The message is: You can have a fun-filled, exciting life, without hurting yourself if you "ThinkFirst." ThinkFirst has chapters throughout the United States and in other countries.

### Features:

- Separate resource pages for kids, youth, and teens
- Fact sheets and prevention tips
- Links to local chapters for speakers
- Order form for educational products

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

The Children's Safety Network (CSN) is a national resource center for the prevention of childhood injuries and violence. It is designed to assist states in building their capacity to prevent injuries and violence against children.

### Features:

- Under “Publications and Resources”
  - Links to publications a wide variety of prevention topics

Additional Resources:

**Safe Kids Georgia**

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

**Georgia Traffic Injury Prevention Institute**

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

**Governor's Office of Highway Safety**

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