



Welcome to the SCI-FYI II, the second edition of the SCI-FYI (Spinal Cord Injury – For your Information: A Guide to Resources for Individuals with SCI). The first edition was completed in February, 1997 and recently revised in January, 2001.

The SCI-FYI is a comprehensive resource guide intended for anyone in Santa Clara Valley needing information on services related to spinal cord injury – from the rehab professional looking for services to help a client, to the individual with a spinal cord injury seeking to improve his or her personal situation. As stated in the previous edition of the SCI-FYI, and as with any directory of community agencies, it will need updating by the time it is published, but the majority of information should remain current and valuable for those seeking resources. All of the agencies listed in the SCI-FYI are also included in the Appendix to help locate information quickly.

The SCI-FYI was compiled primarily from information in the Resource Center at the Rehabilitation Research Center for TBI and SCI, and continues to include primarily local (Northern California) resources. However, state and national resources that may be of particular importance to individuals with SCI are also included. **We do not endorse any of the resources nor make any guarantees regarding the information and services included in this directory.**

We hope you find that the SCI-FYI meets your needs for a resource that provides information on the range of services for individuals with spinal cord injuries in the Santa Clara Valley area. If you have potential additions or deletions for the SCI-FYI, or have any suggestions for the resource guide, please write, FAX, telephone or e-mail me at the address or phone number below. We hope that future editions of the SCI-FYI will continue to assist you in your efforts to improve the lives of individuals with spinal cord injuries and their families.

The SCI-FYI is available free and in its entirety online at <[www.tbi-sci.org/scifyi](http://www.tbi-sci.org/scifyi)>.

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The revision of this resource guide would not have been possible without the hard work and dedication of Sherri Rogers who spent endless hours on the phone contacting the agencies and verifying information.

Jerry Wright, Administrator for the Rehabilitation Research Center for TBI and SCI, was responsible for the layout, design, and indexing of the revised SCI-FYI.

John Hatten was a co-worker at the Traumatic Brain Injury Project and editor of the third and fourth editions of the Traumatic Brain Injury Resource Directory (TBIRD). John's outstanding work on the TBIRD provided us with a working model for the SCI-FYI, and made the seemingly insurmountable task of compiling such a guide possible in the first place.

Diana Harrison from Therapeutic Recreation at Santa Clara Valley Medical Center provided thorough and valuable information on recreation, leisure and transportation resources in the original version of the SCI-FYI.

This resource guide was peer reviewed by Tamara Bushnik, PhD, Mary Lou Gustafson, RN, BSN and Kazuko Shem, MD. The time and effort they put forth to give valuable input is much appreciated.

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And lastly, those of you who provided us with updated and accurate information should be acknowledged for your contributions to this SCI Resource Guide and, more importantly, for enriching the lives of individuals with spinal cord injury.





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### A. Index of Agencies/Facilities





### **Finding information**

- Start with the Table of Contents.
- See if you can find the topic that you are interested in.
- Look through the chapter to see if there is a resource that can help you.
- If you find one, you may want to attach a post-it tab so that you can find the page later.
- Write down all of the information that you will need to make your phone call:  
agency name, telephone number, name of contact person.

You may also look up resources in the Index. You can find them listed by their name, and also by the city they are located in (handy if you have issues with transportation).

If you are unable to find a resource that will help you in this directory, a good first step would be to call your local Independent Living Center (Chapter 13). They will have a good idea of what is available in your area. A second step would be to call or email us (Rehabilitation Research Center for TBI & SCI). We have a SCI resource specialist who may be able to help. Call us at 408/295-9896 extension 24, or email us at [scifyi@tbi-sci.org](mailto:scifyi@tbi-sci.org)

### **Preparation for making a phone call**

When you are making a phone call be sure to prepare in advance so that you have all of the information in front of you and you have paper to write down the information you receive.

Before you call, it is very important to know what you want. You will be far more successful if you can make a specific request rather than just asking for “help”.

### **Making the call**

Introduce yourself and give a brief description of your situation. Ask about the services that they provide. The most important point is to remember to NOT GIVE UP at the first sign of resistance. Sometimes people either don't understand your request or are not sure how they can help you. Sometimes you may need to explain your request in several different ways. Many of the agencies/individuals listed in this guide do not work only with individuals with spinal cord injuries. You may need to describe your issues and/or problems. Sometimes an agency may not be able to help you, but the person you are talking with can make other suggestions. You will also find that some of the services are no longer offered, or the agency is no longer in business.

### **Documenting the call**

You will definitely want to write down:

- Who you talked with.
- Can they help?
- Are you supposed to call back, or do something else to follow-up?
- Did they give you other suggestions?





The **Top Ten List** is a new addition to the SCI-FYI. Here are the most useful and most used resources within the SCI-FYI. These are the resources that we use every week to answer requests emailed to us from around the globe.

*Compiled at the home office in San Jose, California, here are the SCI-FYI's top ten resources.*

- |   | <b>Chapter(s)</b> |
|---|-------------------|
| <b>1. Spinal Cord Injury Information Network (UAB)</b><br>Website: < <a href="http://www.spinalcord.uab.edu">www.spinalcord.uab.edu</a> > <ul style="list-style-type: none"><li>• Excellent resource - very useful</li><li>• Can access 18 fact sheets with information on a wide variety of topics relevant to SCI. Some fact sheets are available in Spanish</li></ul>  | <b>9, 21, 22</b>  |
| <b>2. Listing of SCI Self-Care Manuals</b> <ul style="list-style-type: none"><li>• Six self-care/patient education manuals that are excellent resources for information on bowel, bladder, and skin care, how the body's systems are affected by SCI, and psychosocial issues</li><li>• Great tool to use in training a personal care assistant</li></ul>   | <b>3, 9</b>       |
| <b>3. Spinewire Website</b><br>Website: < <a href="http://www.spinewire.com">www.spinewire.com</a> > <ul style="list-style-type: none"><li>• Outstanding website developed exclusively for the SCI community</li><li>• Features many current articles, SCI related news pieces, including research related news</li></ul>   | <b>17, 21</b>     |
| <b>4. A Guide and Resource Directory to Male Fertility Following Spinal Cord Injury/Dysfunction (Booklet)</b><br>Maria J. Amador, BSN, CRRN, Charles M. Lynne, MD, Nancy L. Brackett, PhD, HCLD<br>Miami Project to Cure Paralysis <ul style="list-style-type: none"><li>• An excellent comprehensive resource guide to current and reliable information on male fertility following SCI</li><li>• Available free of charge</li></ul> | <b>23</b>         |

# SCI-FYI's Top Ten List

|   | <b>Chapter(s)</b>                      |
|---|--|
| <b>5. Through the Looking Glass</b><br>Berkeley, CA<br>Website: <www.lookingglass.org> <ul style="list-style-type: none"><li>• Serves families in which one or more members, whether parent or child, has a disability or medical issue</li><li>• Clinical and supportive services, training and research</li></ul>   | <b>15</b>                              |
| <b>6. Silicon Valley Independent Living Center</b><br>San Jose, CA<br>Website: <www.svilc.org> <ul style="list-style-type: none"><li>• Personal care assistant recruitment and referral; training in the management of personal care assistants</li><li>• Advocacy and legal services</li><li>• Information and referral regarding available and accessible housing</li><li>• Counseling, individual and group support</li><li>• Independent living skills</li><li>• Vocational services</li><li>• Residential training program</li></ul> | <b>3, 5, 6, 12,<br/>13, 14, 16, 26</b> |
| <b>7. National Spinal Cord Injury Association</b><br>Silver Spring, MD<br>Website: <www.spinalcord.org> <ul style="list-style-type: none"><li>• Resource Center</li><li>• <i>SCI Life</i> magazine</li><li>• In Touch with Kids Network for children with SCI</li></ul>   | <b>6, 21, 22,<br/>23, 24, 25</b>       |
| <b>8. Medline - PubMed, Internet Grateful Med</b><br>Website: <www.nlm.nih.gov/databases/freemedl.html> <ul style="list-style-type: none"><li>• The National Library of Medicine provides two free systems to search medical topics in the MEDLINE database</li><li>• About 11 million references and abstracts are found in this database</li></ul>  | <b>21</b>                              |

# SCI-FYI's Top Ten List

|   | Chapter(s) |
|---|------------|
| <b>9. City of San Jose, Office of Therapeutic Services/<br/>South Bay Wheelchair Athletic Program</b>   | <b>16</b>  |
| San Jose, CA<br>Website: < <a href="http://www.ci.san-jose.ca.us/prns">www.ci.san-jose.ca.us/prns</a> >   |            |
| <ul style="list-style-type: none"><li>• Sponsor a number of programs for individuals with disabilities</li><li>• Support groups</li><li>• Aquatics</li><li>• Wheels on Fire - Junior Wheelchair Sports Team</li><li>• Pacific Spartans - Wheelchair Basketball Team</li><li>• San Jose Sting Quad Rugby Team</li><li>• Water Wheels Swim Team</li><li>• San Jose Steamrollers - Power Soccer Team</li></ul> |            |
| <b>10. Websites for Locating Physicians</b>   | <b>11</b>  |
| Website: < <a href="http://www.aapmr.org">www.aapmr.org</a> >   |            |
| Website: < <a href="http://www.certifieddoctor.org">www.certifieddoctor.org</a> >   |            |
| Website: < <a href="http://www.docboard.org">www.docboard.org</a> >   |            |
| Website: < <a href="http://www.ama-assn.org/aps/amahg.htm">www.ama-assn.org/aps/amahg.htm</a> >   |            |

