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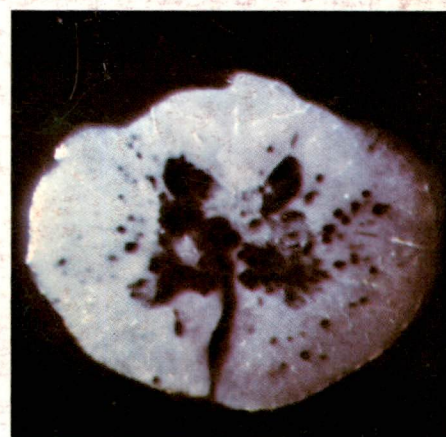
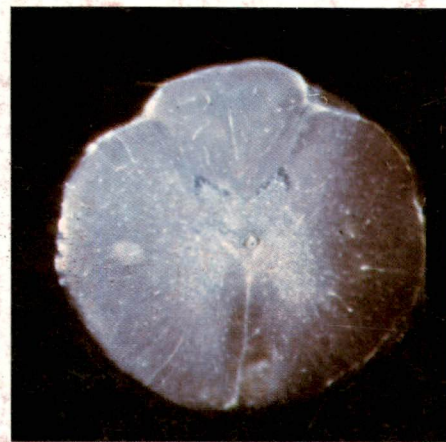
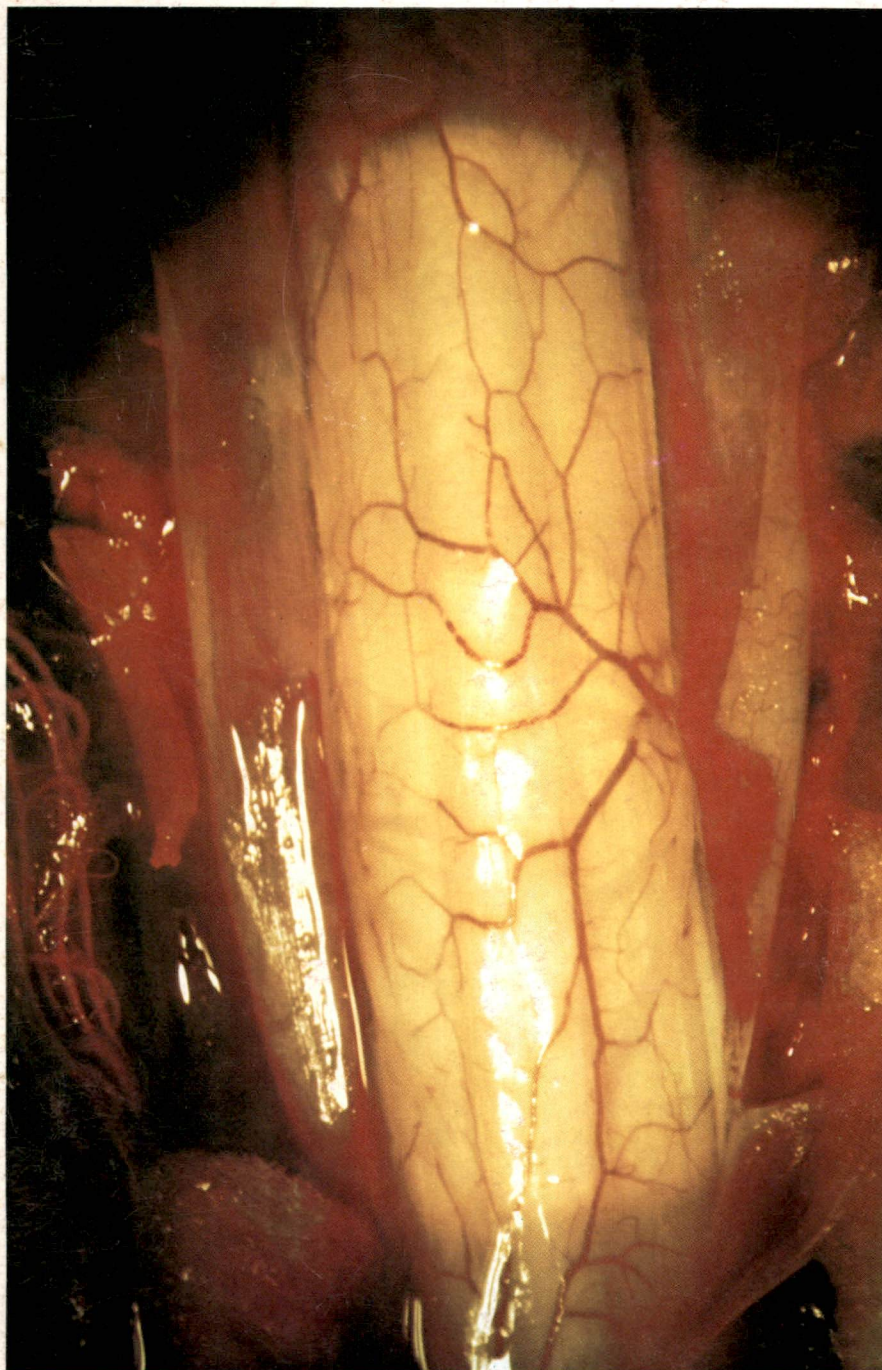
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1981 National Spinal Cord Injury Foundation Convention Journal



SPINAL CORD INJURY IN ANIMALS...GOAL OF STUDIES IS KNOWLEDGE THAT CAN BE USED TO HELP HUMANS

1. Primate spinal cord. 2. Normal cross section. 3. Hemorrhage 15 minutes after injury.
4. Hemorrhage four hours after injury. For details, see page 3.

WE DO MORE THAN GIVE YOU A GOOD LIFT

For many years, making a good lift for the handicapped has been an important part of The Braun Corporation. We offer a tested, time-proven model in both automatic and semi-automatic versions. Recently we introduced the Ramp Rider, a non-automatic ramp that requires manual assistance for both entry and exit. It's modestly priced and easily installed.

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Taking your needs and translating them into a custom planned unit is a specialty with Braun. Whether the unit is a motorhome, mini-motorhome or van, the unit can be carefully planned for a Braun lift and wheelchair floor plan.

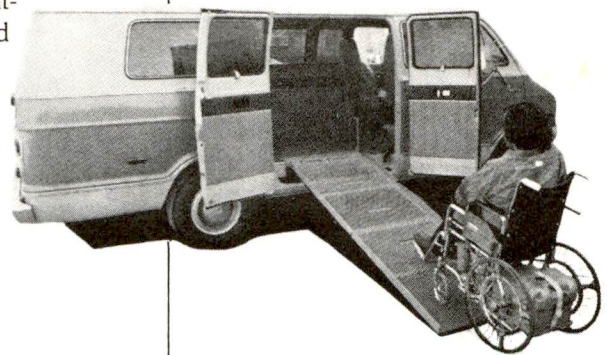
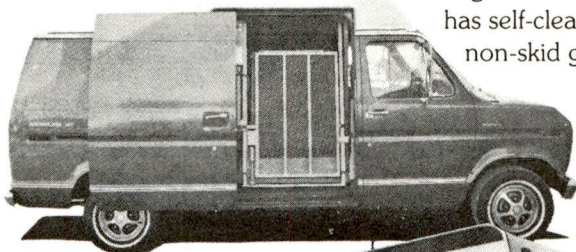


Tri-Wheeler

Here's the product that put Braun in business. This pioneering effort continues to be well received by the handicapped who need this type of mobility.

Ramp Rider

This unique ramp has a computer-designed $\frac{3}{8}$ inch spring to counterbalance the weight of the ramp for smooth, easy folding and moving. Because it's 30 inches wide and 84 inches long, there's greater comfort and more safety. Constructed for side-entry in a van, this ramp is made of Braun-tested strong, light-weight materials and has self-cleaning, non-skid grating.



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In our literature we say, "For the Ups and Downs and Get-Arounds of the handicapped." That's our job and we're sincerely interested in helping in any way we can. Please consider this my personal invitation to call or write me, at any time, regarding any particular question or problem where we could be of assistance.



THE BRAUN CORPORATION

1014 South Monticello
Winamac, Indiana 46996
Telephone 219/946-6157

1981 National Spinal Cord Injury Foundation Convention Journal

Published for the
33rd annual convention
of the
National Spinal Cord
Injury Foundation
August 2-5, 1981
Cincinnati, Ohio

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Write or call for information about
next year's journal.

Convention Theme

Building a Stronger Foundation

Convention Host

Ohio-Kentucky-Indiana Chapter
National Spinal Cord
Injury Foundation

Convention Committee

James Smittkamp
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Richard Veraa
Members of the
Ohio-Kentucky-Indiana Chapter

Contents

- 3 Exhibitors Index**
Where to find out about the products and services of exhibitors at this year's convention.
- 4 Boosters**
Well-wishers who help to keep us solvent.
- 7 Convention Calendar**
What's happening, where, and when.
- 13 Central Office Staff**
Who does what in the Foundation's office in Newton Upper Falls, Massachusetts. Volunteers are welcome.
- 15 Roadracers Push Ahead**
This year in Boston four wheelers beat the fastest runner, and Cable set a new women's record. It was the fifth year for the National Wheelchair Marathon.
- 17 A New Beginning**
McHugh describes Foundation progress during the past 33 years and during the first year of the current reorganization plan. We are achieving — and exceeding — our goals.
- 21 Foundation Directory**
Officers, directors, committees, chapters, staff.
- 26 What Is Spinal Cord Injury?**
And what can we do about it?
- 31 Research Division Staff**
The Foundation's office in Lauderhill, Florida, is responsible for research programs, including fellowships, conferences, and publications.
- 35 Designer Genes Take Dominant Position in Fellowship Awards**
The Foundation is funding fellowships for three young scientists who will study regeneration in the central nervous system. Two will use techniques of genetic engineering, including alteration of genes in recombinant DNA studies.
- 38 New Approaches to the Problem of Regeneration in the Central Nervous System**
Grafstein explains how scientists attempt to understand the behavior of animal and human nerve cells. Laboratory findings in animals may ultimately point the way toward techniques that can be used to reverse the effects of spinal cord injury in human beings.
- 46 Independent Living Programs in the United States Today**
There are now more than 100 independent living organizations in this country. Spinal cord injured persons account for a large proportion of the individuals served.
- 53 Some Thoughts on the Care and Keeping of Attendants**
Smith has some suggestions for disabled people who have trouble hanging on to their personal care attendants. Employers can make the job more — or less — attractive.
- 56 Advertisers Index**
A list of enterprises and organizations that care about the people who read this journal.

*The Rehabilitation
Institute
of Chicago*



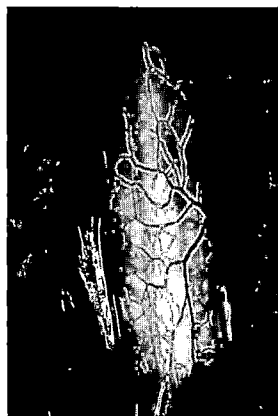
salutes

*The National
Spinal Cord Injury
Foundation*

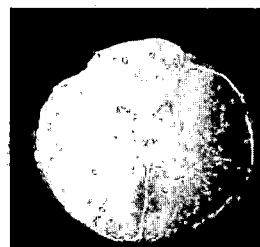


*Rehabilitation Institute of Chicago
345 East Superior, Chicago, Illinois 60611
(312) 649-6179*

Cover Photos



1



2



3



4

On the cover of this journal are photographs obtained in studies of spinal cord injury in animals. The goal of these studies is to understand the changes that occur after injury and to devise means of preventing or reversing damage.

1. Back (dorsal) view of an uninjured monkey spinal cord exposed following laminectomy. The spinal cord coverings (dura and arachnoid mater) have been opened, and surface nerve roots and blood vessels are exposed.

2. Cross section of an uninjured cat spinal cord following injection of a fluorescent indicator of blood flow, thioflavin-S. The butterfly pattern in the center of the spinal cord is the gray matter, which gets its name from its unstained color. The grayness is due to rich vascularity and the presence of many nerve cell bodies (neurons). The thioflavin-S stain causes the gray matter to fluoresce with a light blue color. The surrounding purple area is the white matter, which gets its name from its unstained color. Its major components are extensions of nerve cells called axons, which are white in color. Relatively few nerve cells and blood vessels are present.

3. Cross section of a cat spinal cord 15 minutes after an irreversible paralyzing injury of the dorsal (back) aspect. The thioflavin-S stain shows that a good blood supply is maintained at this point in all areas except regions of hemorrhage, which appear black in color. It should be noted that the early spinal cord damage is mostly limited to the gray matter, because its composition of blood vessels and nerve cells makes it more susceptible to injury than the white matter, which has relatively fewer blood vessels and nerve cells.

The only major area of white matter damaged is directly under the area of impact from the contusion (drop-weight) injury.

4. Cross section of a cat spinal cord four hours after injury. Injection of thioflavin-S shows the severe hemorrhage and destruction of the central gray matter (the butterfly pattern) and the lack of blood supply (ischemia) in the gray matter. The areas of hemorrhage and decreased blood supply have spread into the adjacent white matter, and only the most peripheral (outermost) areas of white matter have preserved blood supply (perfusion). The gray matter is the nerve center of the spinal cord. It receives and sends messages (connecting and directing) to and from the brain and other levels of the spinal cord. The white matter serves as a sort of telephone cable, carrying messages up and down its long axons (tracts). In spinal cord injury, damage to the gray matter has its greatest effect on local function at and near the level of injury, while the loss of ability to move and feel below the level of injury is due to white matter (long tract) damage. The fact that this occurs several hours later than the gray matter damage that occurs in the first minutes and hours gives researchers and clinicians a goal: to be able to limit the spread of destruction and salvage neurological function by treating patients medically or surgically within the early hours following spinal cord injury.

Acknowledgements—We would like to thank Dr. G. Dohrmann (University of Chicago), Dr. B. Green (University of Miami and Miami Veterans Administration Hospital), and Dr. T. Khan (Hines Veterans Administration Research and Development Center) for material used on the cover.

Exhibitors

As the journal goes to press, the following companies are planning to have exhibits at the convention. Call or write for information about products and services.

Amigo Sales of Western Ohio
3915 Greenview Drive
Toledo, Ohio 43606
Phone: (419) 474-4304

Encyclopedia Britannica
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Chicago, Illinois 60611
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Health Aid Services Inc.
6225 Colerain Avenue
Cincinnati, Ohio 45239
Phone: (513) 521-6100

Trans-Aid Corporation
1609 E. Del Amo
Carson, California 90746
Phone: (213) 774-7023

Chesborough-Ponds
33 Benedict Place
Greenwich, Connecticut 06830
Phone: (203) 661-2000

Everest & Jennings Inc.
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Los Angeles, California 90066
Phone: (213) 478-1057

Prentke Romich
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Shreve, Ohio 44676
Phone: (216) 567-2906



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The National Spinal Cord Injury Foundation thanks these individuals, organizations, and institutions for their support of the 1981 convention journal.

Achievement: National Voice of the Disabled

North Miami, Florida

"Rob" C. Adair

Santa Fe Springs, California

Arthur W. Allen Jr.

Washington, D.C.

American Academy of Orthotists and Prosthetists

Alexandria, Virginia

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Alexandria, Virginia

American Orthotic and Prosthetic Association

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Architectural Barriers Action League

Tucson, Arizona

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Cincinnati, Ohio

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Shaker Heights, Ohio

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Chicago, Illinois

Case Management Inc.

Englewood, Colorado

Central Massachusetts Rehabilitation Center

Worcester, Massachusetts

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Shaker Heights, Ohio

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Englewood, Colorado

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Courage Center

Minneapolis, Minnesota

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St. Petersburg, Florida

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University of Miami School of Medicine

Miami, Florida

Department of Physical Medicine and Rehabilitation

Georgetown University

Washington, D.C.

Department of Rehabilitation Medicine

University of Maryland and Montebello Hospitals

Baltimore, Maryland

Barry N. Eigen

Milwaukee, Wisconsin

Arthur T. Evans

Cincinnati, Ohio

Janet & Allan Fay

Washington, D.C.

Peter Fedorko

Rochester, Minnesota

Dr. & Mrs. S. Norman Feingold

Bethesda, Maryland

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Boston, Massachusetts

Gaylord Hospital

Wallingford, Connecticut

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Franklin Square, New York

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La Grange, Illinois

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Bethesda, Maryland

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Elizabeth City, North Carolina

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Mark Moser
Crawfordsville, Indiana

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Washington, D.C.

**National Association of the
Physically Handicapped Inc.**
Harper Woods, Michigan

National Easter Seal Society
Chicago, Illinois

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JoAnn & Bruce Tompkins
Maineville, Ohio

Phil Veraa
Lauderdale Lakes, Florida

Rich Veraa
Lauderdale Lakes, Florida

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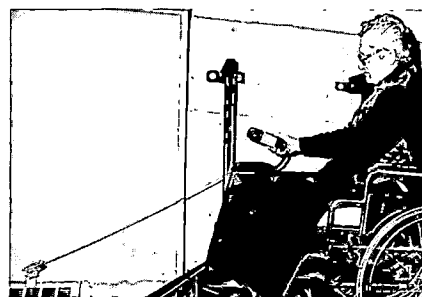
Mr. & Mrs. Leon Weiss
New York, New York

**West Virginia Mountaineer Chapter
National Spinal Cord Injury
Foundation**
Charleston, West Virginia

Sharon H. Wilkin
Vienna, Virginia

ANOTHER BOOSTER

Another booster is the Cheney Company of New Berlin, Wisconsin, which in 1979 donated a stairway elevator to make both levels of the Foundation's Central Office accessible. The model installed was the Cheney Wheelchair Lift III. See advertisement on inside back cover.



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Visit the IYDP booth at the 1981 Ohio State Fair, August 14-30 in Columbus, and watch for special IYDP exhibits throughout the entire fairgrounds!

For information about Ohio IYDP activities, call the state coordinating agency:

The Rehabilitation
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Americans**

Best Wishes for a
Successful Convention

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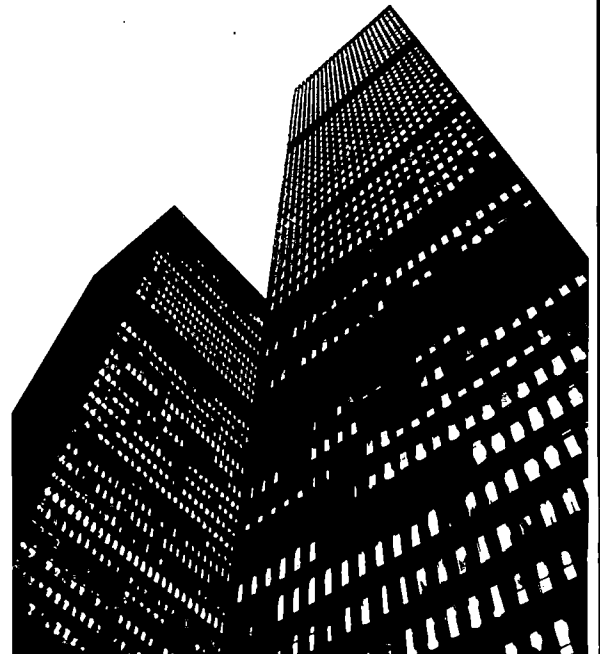
Consulting Electrical Engineer

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PVA wishes success to the NSCIF in Cincinnati

Paralyzed Veterans of America
4350 East-West Hwy., Suite 900
Washington, D.C. 20014
(301) 652-2135

Michael Delaney, President
R. Jack Powell, Executive Director



Convention Calendar

Sunday, August 2

8:00-5:00 Coatroom

Registration Opens

9:00-5:00 Harding Room

Convention Headquarters Open

9:00-12:00 Taft I & II

Chapter Liaison Panel

Chairperson: Jean S. Logan
Foundation Vice President for
Chapter Growth and Development
and Public Relations Manager
Curative Rehabilitation Center
Milwaukee, Wisconsin

1:30-3:30 President II

**Coping Issues: Impact of Spinal Cord Injury
on Families**

Chairpersons: Joan Redden, Clinical Psychologist
and Nancy Buhrmann, Social Worker
Department of Physical Medicine and
Rehabilitation

University of Cincinnati Medical Center
Cincinnati, Ohio

Panelists: Jonathan and Sharon Wilkin
National Capital Area Chapter
National Spinal Cord Injury Foundation
Washington, D.C.

1:30-4:00 Taft I & II

Chapter Training

Chairperson: John Schatzlein

Administrator/Counselor

HOMEWORK Program

Control Data Corporation

Minneapolis, Minnesota

• 1:30 **Objectives of Session**

• 1:45 **Chapter Organization and Development**

Presentations by:

Metrolina Chapter

Charlotte, North Carolina

National Capital Area Chapter

Washington, D.C.

Ohio-Kentucky-Indiana Chapter

Cincinnati, Ohio

Oregon Trail Chapter

Portland, Oregon

• 2:30 **Chapter Dynamics**

• 3:15 **Chapter Problem-Solving Through
Experimental Learning**

4:15-6:00 Taft I & II

Foundation Board Meeting

6:00-8:00 President I

Reception: Exhibits Open

Master of Cermonies: Karl Beck
Convention Exhibit Chairperson
and Southern Division Manager
Braun Corporation
Clearwater, Florida

Monday, August 3

9:00-5:00 Coatroom

Registration

9:00-5:00 Harding Room

Convention Headquarters Open

9:30-5:00 President I

Exhibits Open

8:30-9:30 President II

Kickoff Breakfast

• **Opening Remarks**

Myron Swatt, President

National Spinal Cord Injury Foundation
and Executive Vice President

Encore Service Systems of Florida Inc.
Boca Raton, Florida

C. Larry Rossiter, President

Ohio-Kentucky-Indiana Chapter

National Spinal Cord Injury Foundation
Maineville, Ohio

• **Welcome to Cincinnati**

The Honorable David S. Mann

Mayor of Cincinnati

• **Introduction of Exhibitors**

Karl Beck

9:30-12:00 President I

Special Exhibit Viewing

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Phone (305) 843-3360

Convention Calendar

from page 7

Monday, August 3 (cont.)

9:45-4:15 Taft I & II

Chapter Liaison Panel Work Session

(box lunch available)

Chairperson: Jean S. Logan

1:30-4:00 President II

Spinal Cord Injury Care

- **Prevention and Management of Pressure Ulcers**

John Aseff, Physiatrist

Department of Physical Medicine and

Rehabilitation

University of Cincinnati Medical Center

Cincinnati, Ohio

- **Bowel Programs**

John Aseff

- **Management of the Neurogenic Bladder**

John Aseff

- **Drugs Commonly Used in Spinal Cord Injury Care**

Randall L. Braddom, Chairperson

Department of Physical Medicine and

Rehabilitation

University of Cincinnati Medical Center

Cincinnati, Ohio

- **Management of Autonomic Hyperreflexia**

Randall L. Braddom

4:30-6:00 Taft I & II

Foundation Board Meeting

Evening

Riverboat Ride with Dinner on Board

Tuesday, August 4

9:00-5:00 Coatroom

Registration

9:00-5:00 Harding Room

Convention Headquarters Open

9:00-5:00 President I

Exhibits Open

9:00-10:00 President II

Annual Meeting of Members of the National Spinal Cord Injury Foundation

Myron Swatt, President

National Spinal Cord Injury Foundation

Concurrent Sessions:

10:00-12:00 President II

Coping with Spinal Cord Injury

- **Total Living Concepts**

C. Larry Rossiter

- **Services for Independent Living**

Doris Brennan, Executive Director

Services for Independent Living Inc.

Cleveland, Ohio

10:00-12:00 Taft I & II

Government and Research Issues

Chairperson: Barth A. Green

Vice President for Research

National Spinal Cord Injury Foundation

and Assistant Professor

Department of Neurological Surgery

University of Miami School of Medicine

Miami, Florida

- 10:00 **Opening Remarks**

Barth A. Green

- 10:15 **Science and the Congress**

Speaker To Be Announced

- 10:40 **Science and the White House**

Denis J. Prager, Associate Director

Office of Science and Technology Policy

Executive Office of the President

The White House

Washington, D.C.

- 11:05 **Implementation of Science Policy**

Murray Goldstein, Acting Director

National Institute of Neurological and

Communicative Disorders & Stroke

National Institutes of Health

U.S. Public Health Service

Bethesda, Maryland

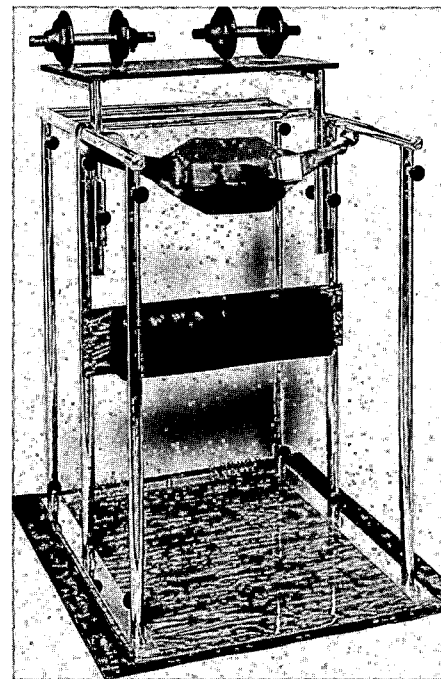
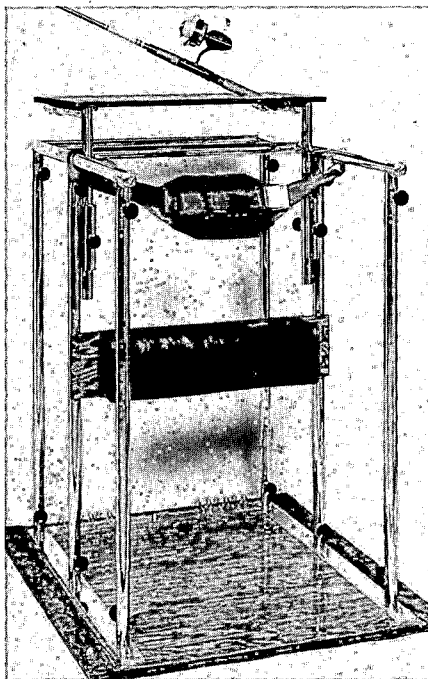
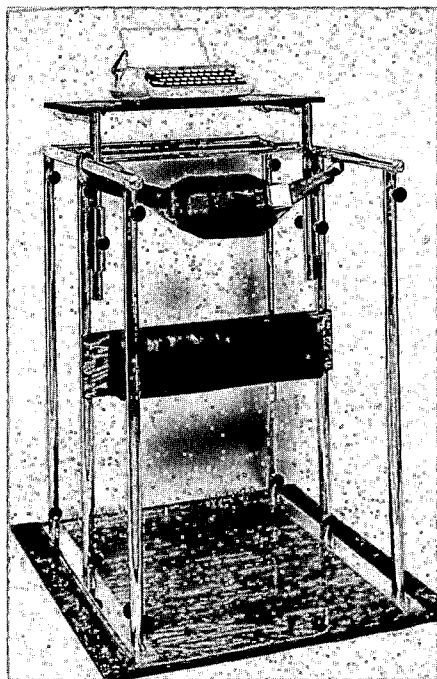
- 11:30 **Discussion and Questions**

continued on page 11

* PORTABILITY

* MOBILITY

* FREEDOM



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Convention Calendar

from page 9

Tuesday, August 4 (cont.)

Concurrent Sessions:

1:30-4:00 President II

Care/Coping: Workshop on Communication and Assertion Skills

Joan Redden

Gail Prather, Consultant to Management
Procter and Gamble Inc.
Cincinnati, Ohio

1:30-4:00 Taft I & II

Chapter Training: Review and Critique of Problems and New Projects

John Schatzlein

4:15-6:00 Taft I & II

Foundation Board Meeting

Evening

Baseball Game — Cincinnati Reds vs. Los Angeles Dodgers
or Tour of City

Wednesday, August 5

9:00-5:00 Coatrium

Registration

9:00-5:00 Harding Room

Convention Headquarters Open

9:00-12:00 President II

Recent Developments in Spinal Cord Injury Research

Chairperson: Bernice Grafstein

Professor of Physiology

Cornell University Medical College

New York, New York

and Chairperson

Scientific Advisory Committee

National Spinal Cord Injury Foundation

● **9:00 Opening Remarks**

Bernice Grafstein

● **9:15 Regeneration and Plasticity in the Central Nervous System**

Irvine McQuarrie, Professor

Department of Anatomy

Case Western Reserve University

Cleveland, Ohio

● **9:40 Neurological Growth Associated Proteins**

J.H. Pate Skene, Research Fellow

Department of Neurobiology

Stanford University Medical Center

Palo Alto, California

● **10:05 Stimulation of Nerve Fiber Growth**

Albert Aguayo, Professor

Departments of Neurology and Neurosurgery
and Medicine

McGill University

Montreal, Canada

● **10:30 Break**

● **10:50 Spinal Cord Repair: Experimental Outlook**

Eugene D. Means, Director of Neurology

Veterans Administration Hospital

Cincinnati, Ohio

● **11:15 Discussion and Questions**

Concurrent Sessions:

1:30-3:30 President II

Care/Coping Issues in Spinal Cord Injury

● **Stress Management**

Joan Redden

Nancy Buhrmann

● **Model Systems Care**

Terry Carle, Co-Director

Midwest Regional Spinal Cord Injury Care-System

Northwestern University McGaw Medical Center

Chicago, Illinois

1:30-3:30 Taft I & II

Chapter Training: Final Critique, Strategies for Work Plans, and Chapter Goals

John Schatzlein

3:45-4:45 Taft I & II

Foundation Board Meeting

6:00 Taft I & II

Reception and Awards Banquet

The Calumet Region Chapter

300 West 21st Avenue, Gary, Indiana 46407

sends best wishes to members and friends of the

National Spinal Cord Injury Foundation

at its

annual convention!

Varied Opportunities for physical therapists

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Curative

Curative Rehabilitation Center

9001 Watertown Plank Road
Milwaukee, WI 53226
Phone (414) 259-1414



National
Spinal Cord
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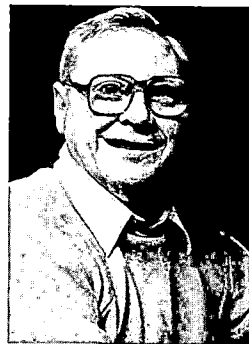
Susan Hayward



Noemi Zakarian



Isabelle Barrows



Tom Spinks



Frances Phillips

The Central Office staff now consists of five full-time employees and eight part-time volunteers. Their teamwork has enabled reorganizing and refocusing the Foundation's resources during the past year. Here are some specifics to go with the names that are becoming familiar to those who call, write, or visit the Foundation's office in Newton Upper Falls, Massachusetts.

Robert McHugh, Executive Director since July 1, 1980, oversees all staff activities and maintains communication with the membership of the Foundation, the Executive Committee, and the Board of Directors. Bob has final responsibility for all programs and functions: for example, fund raising, public relations, fiscal management, chapter development, interagency and government relations, and contract negotiations.

Ann Ford, Director of Operations, manages administrative functions including membership systems and orientation and training for volunteers. In addition, Ann maintains formal relationships with other organizations, manages personnel policies and programs, and produces reports required by the Internal Revenue Service and federal and local governments. Ann also is responsible for staffing meetings of the Board, Executive Committee, and Finance Committee and for preparing necessary documentation.

Susan Hayward, Program Associate, coordinates the Foundation's Professional Careers Program, which is sponsored by Projects with Industry. The program places individuals with severe physical disabilities in professional positions that offer potential for career growth in the public and private sector. Susan also assists with development programs, supervises student interns working on resource coordination, and coordinates the National Wheelchair Marathon.

Noemi Zakarian, bookkeeper, receipts all monies, sends acknowledgements, keeps all ledgers, maintains financial files, and prepares bank deposits.

Isabelle Barrows and Lynn Bianchino are our Central Office secretaries. Isabelle and Lynn work and go to secretarial school alternate weeks. Typing, filing, shorthand, and answering the telephone are a few of the duties they perform.

Peggy Mayo, Associate Resource Coordinator, is a student intern. She is responsible for coordinating the resources available in Massachusetts for spinal cord injured individuals. Areas of interest include accessibility, housing, transportation, and adaptive equipment. Peg makes monthly visits to the local spinal cord injury centers and meets with patients to discuss community resources.

The Central Office is fortunate to have the support of seven volunteers who donate a total of more than 75 hours each week. These volunteers, Tom Spinks, Kevin Boyd, Pauline Boyd, Natalie Wilfand, Mona Noon, Millie Breger, Ruth Zuroff, and Frances Phillips, perform a variety of clerical and administrative duties. They help out with typing, filing, sending out publications and membership cards, updating the Foundation's mailing list, bulk mailing projects, collating, xeroxing, etc. The Central Office could not function without these volunteers and would welcome additional help from anyone who is willing to donate time. □

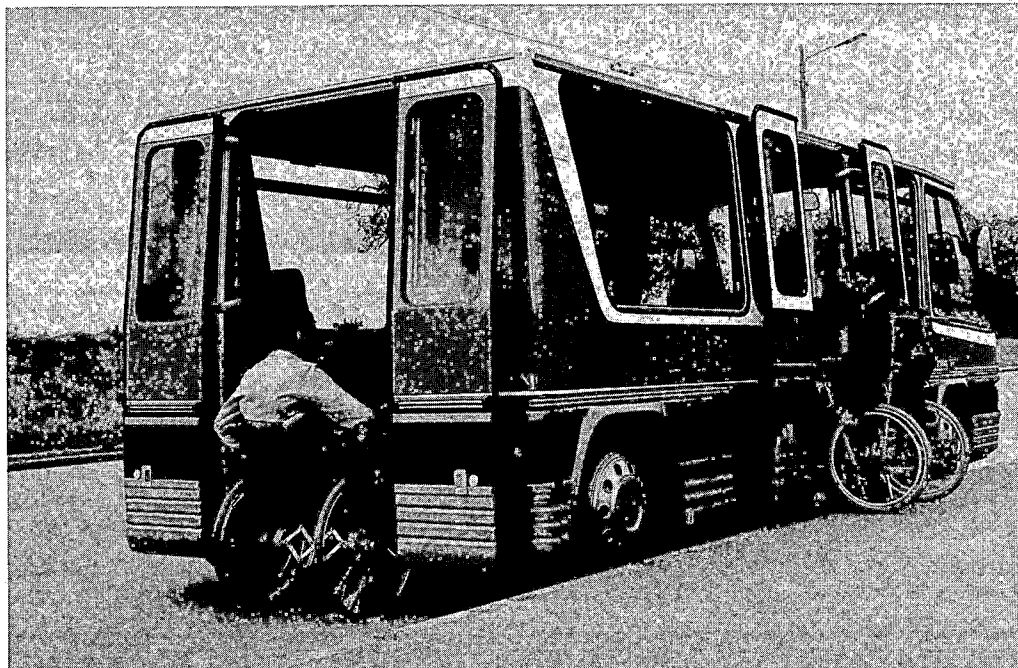


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In 1977, seven wheelchair athletes entered the first National Wheelchair Marathon. Hall was champion that year, finishing the race in 2 hours, 40 minutes, 10 seconds. Sharon Rahn from Champaign, Illinois, was the only female in the 1977 race and finished fifth.

In 1978, the marathon expanded dramatically. The field of wheelchair competitors increased to 18, including two women. George Murray of Tampa, Florida, pushed the distance in 2 hours, 26 minutes, 59 seconds. This feat improved on the previous record by 13 minutes, 11 seconds. The women's winner in 1978 was Susan Shapiro from Berkeley, California, who finished in 3 hours, 52 minutes, 35 seconds.

The 1979 race was difficult due to adverse weather conditions. Nonetheless 15 men and women in wheelchairs competed. Ken Archer, by then a three-time participant, crossed the finish line in 2 hours, 38 minutes, 59 seconds. Sheryl Bair of Sacramento, California, set a new women's record with a finishing time of 3 hours, 27 minutes, 59 seconds.

1980 brought the nation's top 20 wheelchair athletes to Boston. The race began at 11:45 a.m. as Marathon Sports Chairpersons Russ Francis, tight end for the New England Patriots, and Darryl Stingly, former wide receiver for the Pa-

triotics, sounded the gun. One hour, 55 minutes later, Curt Brinkman of Orem, Utah, crossed the finish line, surpassing the record set by George Murray in 1978 by almost 32 minutes. Brinkman's time was more than 17 minutes faster than that of Bill Rodgers, the foot-racer who won the Boston Marathon that year. The first place female was Sharon Limpert of Minneapolis, Minnesota, who beat the previous women's record by nearly 40 minutes.

In 1981, 18 wheelchair athletes, including four women, entered the race. After pushing his way over the 26-mile, 385-yard course in 2 hours, 41 seconds, Jim Martinson of Puyallup, Washington, became the winner of the 5th Annual National Wheelchair Marathon. Martinson and three other wheelchair athletes outpaced the fastest able-bodied runner in the Boston Marathon. Running 38 minutes behind Martinson, Candace Cable from Las Vegas, Nevada, crossed the finish line and established a new record for the women's division: 2 hours, 38 minutes, 41 seconds.

The Foundation's purpose in sponsoring and directing the National Wheelchair Marathon is to educate the general public about the athletic achievements and potential of persons who use wheelchairs for mobility. The National Wheelchair Marathon is the premier athletic event of wheelchair road racing and is internationally recognized in the world of wheelchair sports. □

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A New Beginning

by Robert J. McHugh

The last 30 years have brought dramatic changes in the outcome of, knowledge about, and attitude towards spinal cord injuries with respect to the consumer, the government, and the public. Death, dependency, institutionalization, non-productivity, and hopelessness are no longer automatic results of a spinal cord injury. Acute, rehabilitative, and chronic medical treatment have become specialized and comprehensive in many areas. Public awareness, private sector support, and government lobbying have brought increasing financial support and scientific attention to basic regeneration research. New initiatives and improved communication in the scientific community have brought increased hope for an eventual cure. Independent living, peer supports, barrier removal, public and professional education, and resource publications have been developed and are available in many communities. The days of enforced dependence and total isolation are giving way to full access and equality for spinal cord injured persons.

A great deal has been accomplished over a relatively short span of time. This truth is often overlooked as we focus on the problems facing a person with spinal cord injury that have yet to be resolved. I am not suggesting that a lessened amount of attention or demand be placed on the resolution of any aspect

Robert J. McHugh is executive director of the National Spinal Cord Injury Foundation.

of continuing problems. I am suggesting, however, that we identify the strengths that have brought about our current level of success, establish our priorities for investment of time and resources, and continue to work to solve the complex of problems that at one time seemed insurmountable.

The National Spinal Cord Injury Foundation has operated successfully for the past 33 years. It is the only non-governmental, nationally-based organization with a comprehensive approach to spinal cord injury. It represents both the consumer and the professional. The goals of "Care, Cure, and Coping" are addressed by the Foundation's 42 chapters and 5,300 members. Our ability to represent nationally the needs of persons with spinal cord injuries is based upon the input and direction provided through our membership, chapter, and governing structure. Direct service programs — including prevention, public and professional education, peer counseling, hospital visitation, case consultation, independent living, and resource documentation — are being provided through many local chapters to help ensure that needs are met locally while support is provided to address issues at the national level. It is in this way that the Foundation has been instrumental in the development and funding of 11 regional comprehensive treatment centers and six regional acute treatment centers; the drafting, passage, and implementation of the rehabilitation acts of 1973 and 1978, which call for removal of physical, attitudinal, and other barriers; the raising and awarding of private sector funds each year to support regeneration, research efforts; the drafting and passage of legislation to support increased governmental funding for regeneration research; and the continuation of public education efforts to increase awareness of the needs and abilities of persons who have spinal cord injuries.


Our success in the past has been predicated upon three major strengths: our purpose, our energy, and our ability to make necessary changes. These principles have guided our operation during the past year. The completion of this fiscal year has brought the Foundation through the first phase of an overall reorganization plan. The goals for the first year of the three-year plan have been to accomplish the following:

- (1) Establish the systems and staffing necessary to control and properly manage the financial and programmatic operations of the Foundation.
- (2) Reduce our overall operation debt by \$80,000.
- (3) Decentralize the central office operation.
- (4) Increase membership by 10%.
- (5) Set priorities for the national effort to:
 - (a) Establish a fund-raising base to assure ongoing operations and goals;
 - (b) Focus on programs of research, prevention, and acute care;
 - (c) Support chapter growth and operation.
- (6) Create an atmosphere of unity of purpose and effort throughout the Foundation's family.

We have not only met these goals; in some cases we have exceeded them. To summarize briefly, the specifics are as follows:

- (1) We are in control. The Board, Finance Committee, and staff have established a 12-month track record of open

continued on page 19



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A New Beginning from page 17

and accurate management of funds and internal and external communication that has re-built our credibility as an organization.

- (2) Our past debt has been reduced by \$125,000.
- (3) All local services have been decentralized, and chapter communication and support have improved.
- (4) Membership has increased over the past year by 17% (present total: 5,300 members).
- (5) (a/b) The national operation (based in Boston and Fort Lauderdale) has developed a strategy to increase private sector support for the priorities of research, prevention, and acute care. As the national operation becomes stronger and self-sufficient, our chapters will have increased supports to utilize, a unified voice of influence, and resources channeled to support local services.
(c) One new and one former chapter have been issued charters. Four additional groups are in the process of organizing.
- (6) Our organization is once again building a spirit of unity that is only possible through open and direct communication and respect for the needs and abilities of all the members of our Foundation family.

The progress we have made this year is impressive when compared to the task that faced us in July 1980. We have, however, completed only the lesser of the two major objectives that must be achieved for the Foundation to realize success. Our first task was to control and solidify an organization in crisis. We have stopped and reversed the accumulation of debt that was proceeding at a rate of \$150,000 per year. During the past year we produced a surplus of \$125,000. We have brought our Board, Chapters, members,

and staff together through improved communication and direct involvement in solving our immediate problems. Our second and more demanding task, however, is to focus, strengthen, and expand the impact of our efforts through reorganization and fund-raising.

The critical point we have reached is the mid-point between initial success and long-term success. A base has been established that will allow us to complete the rebuilding of our operation only if the commitment, hard work, and vision that went into the first year of reorganization result in expanded effort with more people accomplishing more work. The Foundation is alive and on the way to becoming well. This may cause some to believe that their concern, input, and individual effort are no longer indispensable. Nothing could be farther from the truth. We are an organization of people that is only as strong and as capable as we, its members, make it. There have been times in the past when the Foundation has lost sight of this fact and has suffered for it. We are now at the point—with the continued support and persistence of all our members—that we can complete the overall task we were given in July 1980: to reestablish the National Spinal Cord Injury Foundation's ability to resolve the problems of spinal cord injury.

What has been achieved to date dramatically demonstrates what can be accomplished by a national organization of people determined to solve a specific set of problems. While many groups and individuals have been instrumental in our success, the Foundation has maintained its focus on the issue of spinal cord injury and provided the means by which public and private interests have come together to address relevant needs. The Foundation brings to the work that remains to be done a positive sense of accomplishment, a national reputation, and continuing leadership ability. □

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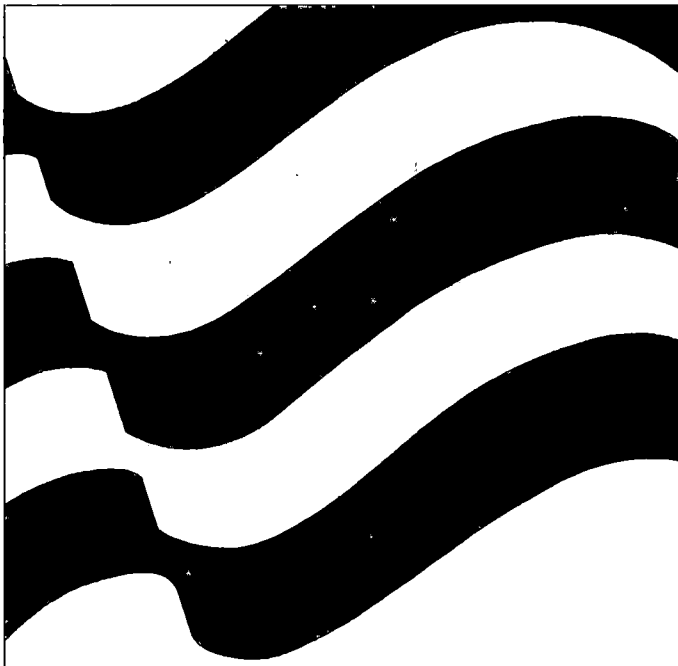
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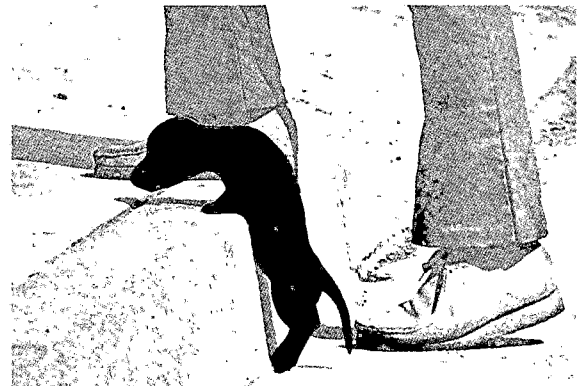
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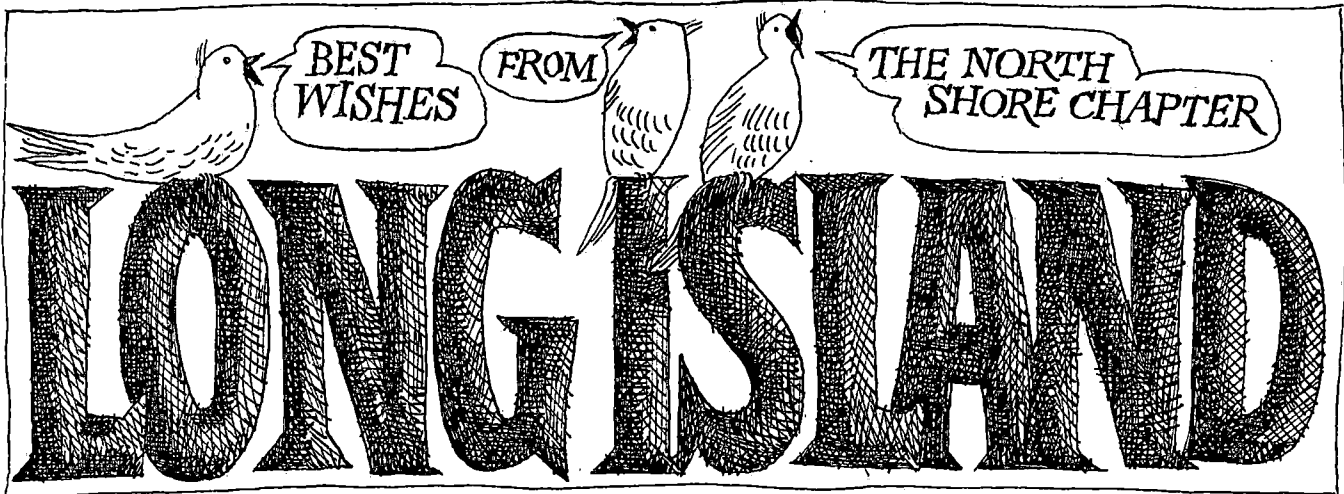
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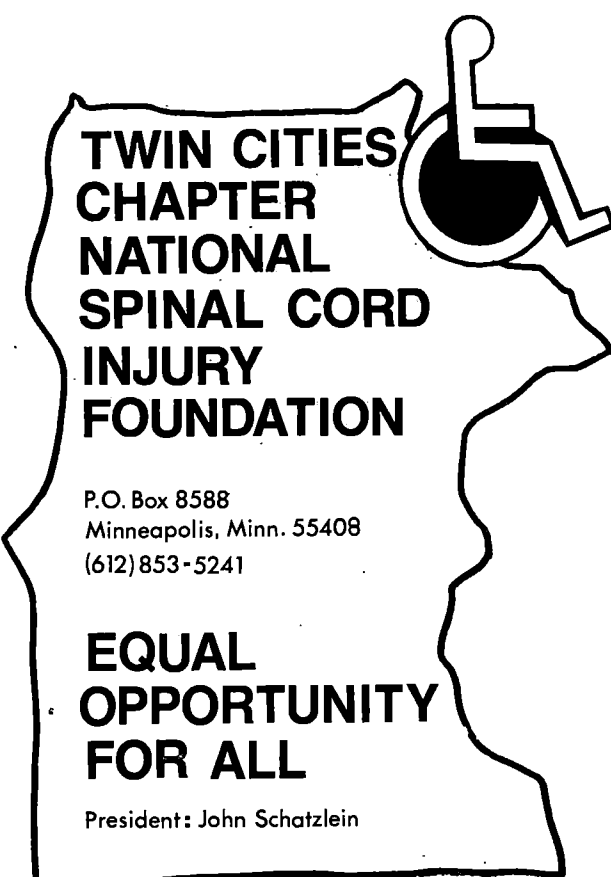
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What Is Spinal Cord Injury?

And What Can We Do About It?

Spinal cord injury is a lesion of the cord that results in paralysis of certain parts of the body and corresponding loss of sensation. Paraplegia refers to paralysis from approximately the waist down. Quadriplegia refers to paralysis from approximately the shoulders down.

The catastrophic nature of spinal cord injury is much more complex than loss of feeling and inability to move. Individuals who experience damage to their spinal cords also contend with impairment of bladder, bowel, and sexual function. Added to this are the psychological effects of adjustments that must be made to social, economic, and emotional ramifications of spinal cord injury.

The major causes of spinal cord injury are motor vehicle accidents (about 50% of the total), falls, diving and other sporting mishaps, and results of violence such as gunshot and stab wounds. The overwhelming majority of injuries, about 80%, are incurred by males who are, in general, between the ages of 15 and 30 when injured.

A comprehensive system is necessary to integrate care, treatment, rehabilitation, and return to independent living in the community. For this reason, regional spinal cord injury systems are under development so that available resources will be effectively coordinated. Much must be done to refine these systems and eliminate gaps in service.

The National Spinal Cord Injury Foundation, formerly the National Paraplegia Foundation, has given priority to improving methods of clinical care, developing more effective equipment and devices, and promoting basic neuroscientific research to find means of regenerating spinal cord tissue. These activities provide for better day-to-day management of spinal cord injury by consumers and providers of service and at the same time explore the long-term possibilities for finding a so-called "cure" for spinal cord injury. The National Spinal Cord Injury Foundation has a Research Division to spearhead efforts in basic and applied research.

In order to assist persons with spinal cord injuries, the Foundation has 60 chapters throughout the United States. Many members are disabled; many are not. Chapter members participate in a variety of activities. They work with local and national officials and agencies to develop better programs and services. They act as community advocates for improved access, housing, transportation, employment, and leisure time activities for disabled people. These are fundamental aspects of living that 250,000 paraplegics and quadriplegics must cope with after they have been rehabilitated and have returned to community life.

More and more persons are getting involved in activities of the National Spinal Cord Injury Foundation. Through the collective efforts of staff, chapters, board members, and other volunteers, the Foundation is improving care, producing results in research, and addressing everyday living issues that confront all wheelchair-users.

It should be noted that the Foundation serves not only persons with spinal cord injuries but also persons who have diseases or conditions the effects of which are similar to those of spinal cord injury. For example, there is multiple sclerosis, which affects young adults, primarily women. Freidreich's ataxia manifests itself during teenage years and appears to run in families. Polio still occurs, primarily in young children, even though vaccines are available. Spina bifida develops before birth during growth of the fetus. Varying degrees of paralysis often result. The individuals affected frequently use wheelchairs and therefore must cope with many of the same problems that confront persons with spinal cord injuries.

What the Foundation Does

There are three basic program goals:

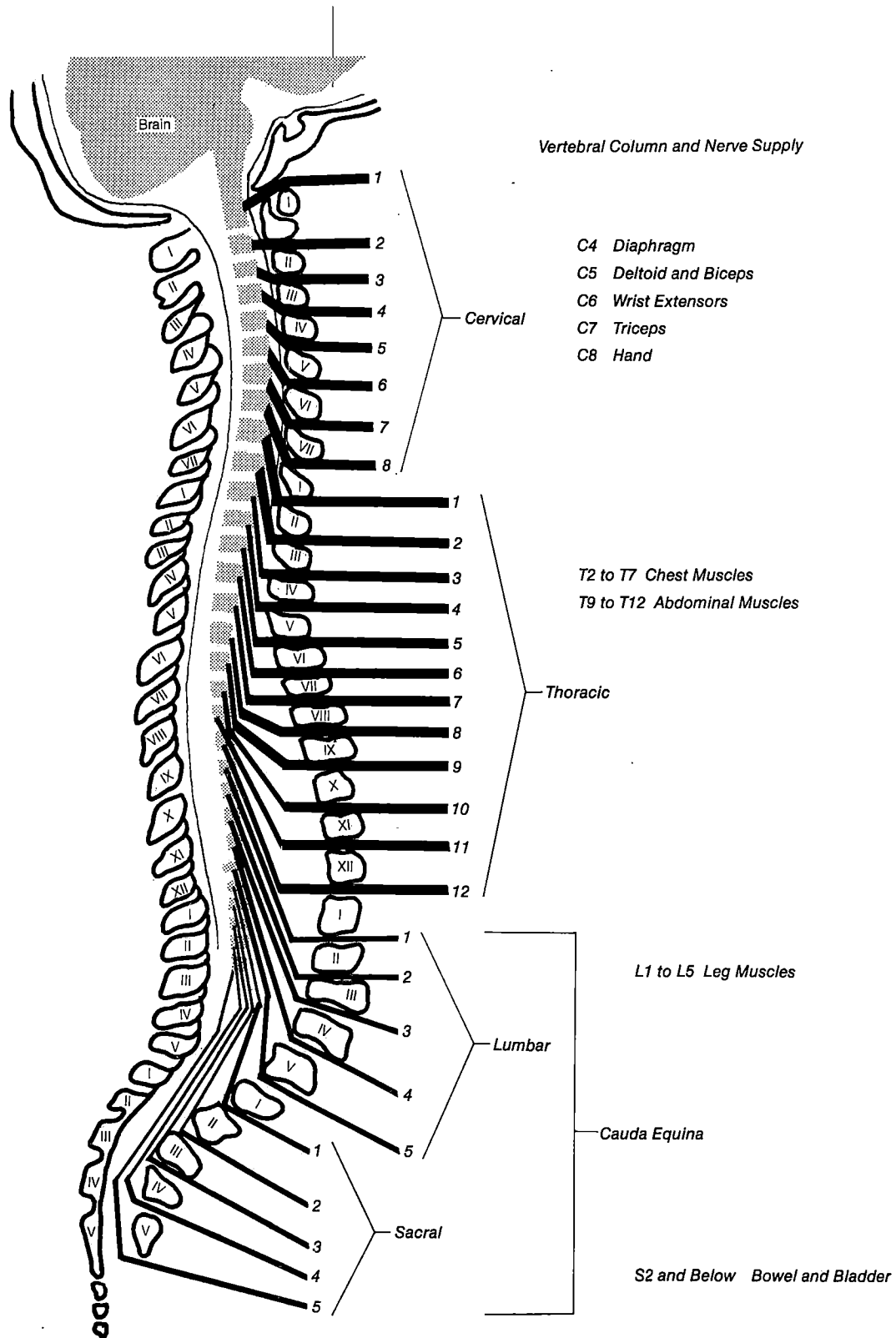
1. The National Spinal Cord Injury Foundation assists in the development of regional systems of comprehensive and integrated care, treatment, rehabilitation, and community

continued on page 29

A paraplegic is a person whose lower extremities and part of whose torso are paralyzed as a result of injury or disease of the spinal cord.

A quadriplegic (also called a tetraplegic) has in addition a paralysis of the hands and a partial paralysis of the arms.

Most paraplegics and quadriplegics have loss of sensation below the level of injury and loss of controlled function of the bladder and bowel.



A person with a spinal cord injury may be a paraplegic or a quadriplegic. This drawing represents a sagittal section of the spine. The vertebrae are labeled with Roman numerals; the spinal nerves are labeled with Arabic numbers. The muscles and organs controlled by various nerves are listed on the right. When spinal cord injury occurs, the level is designated by calling the person, for example, a C4-5 quadriplegic. Paraplegia results from injury at the T1 level or below, and quadriplegia results from injury at the C8 level or above.

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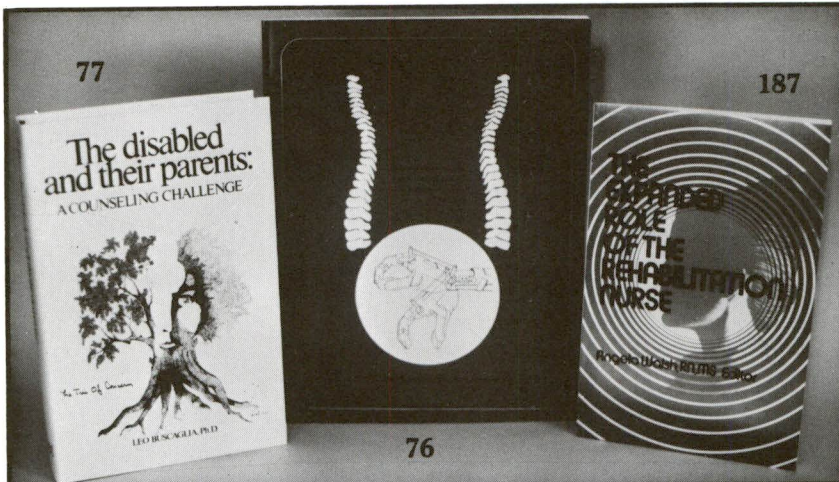
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77 The Disabled and Their Parents: A Counseling Challenge *Buscaglia L.F.*

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76 Spinal Cord Injury: A Treatment Guide For Occupational Therapists *Wilson DJ, McKenzie MW, Barber LM.*

This manual presents general guidelines for evaluating a person with a traumatic injury to the spinal cord. It is especially helpful for occupational therapy interns, and occupational therapists with limited experience who need a broad guideline for planning a treatment program. This manual is also a valuable reference tool for more experienced therapists who do not regularly deal with spinal cord injuries. 90 pp, illus, paper, \$12.00.

187 The Expanded Role of the Rehabilitation Nurse *Walsh A.*

This book is based on a three-day symposium held in California. Its three primary objectives are: to define rehabilitation nursing's new roles and responsibilities; to identify specific educational preparation for both student and practicing nurses; and to identify new ways of contributing nursing expertise to the severely disabled. 1980, 96 pp, paper, \$14.00.

Spinal Cord Injury from page 27

living. The purpose is to serve individuals who become paralyzed as a result of spinal cord injury. Activities include:

- promoting ideal standards of care;
 - documenting available resources;
 - coordinating resources at the local level;
 - providing case consultation services to persons who have recently experienced spinal cord injury and their families;
 - developing and providing independent living services that help high-level quadriplegics and others with severe physical disabilities make the transition from dependent situations to independent community lifestyles;
 - educating professionals about proper methods of providing care and rehabilitation; and
 - implementing a program of public education that focuses on prevention of spinal cord injury and abilities of individuals who have been paralyzed as a result of spinal cord injury.
2. The National Spinal Cord Injury Foundation supports and encourages research aimed at improving care for persons with spinal cord injury and developing a cure for spinal cord injury and disease. To pursue these objectives, the following activities are undertaken:
- promoting neuroscientific research;
 - promoting improved clinical care through professional education and support of research conducted by other agencies and organizations;
 - promoting research to improve equipment and special devices;
 - providing fellowships for postdoctoral researchers working on basic neuroscientific problems;
 - sponsoring biennial conferences on basic neuroscientific research;
 - publishing scholarly research bibliographies; and
 - facilitating exchange of information between and among scientists.
3. The National Spinal Cord Injury Foundation pursues resolution of issues related to the everyday lives of paraplegics and quadriplegics. Problem areas include access, housing, transportation, employment, and leisure. Activities are carried out primarily through the chapter structure of the Foundation. Specifically, chapters:
- provide peer counseling on a person-to-person basis;
 - help through personal contact to motivate individuals with spinal cord injury to establish realistic goals in regard to employment, education, transportation, and adaptation to wheelchair living;
 - distribute information to paraplegics, quadriplegics, and others in regard to equipment, personal care, special devices, and other important resources; and
 - advocate elimination of barriers to independent living for persons who use wheelchairs for mobility.

What You Can Do

The National Spinal Cord Injury Foundation needs your support and involvement. You can help by:

- joining the Foundation;
- volunteering to assist with its local, regional, and national programs;
- contributing money to support the services of the Foundation and identifying others who can help; and
- speaking with your local, state, and national representatives in government about the needs and abilities of spinal cord injured people. □

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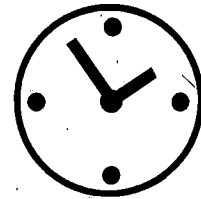
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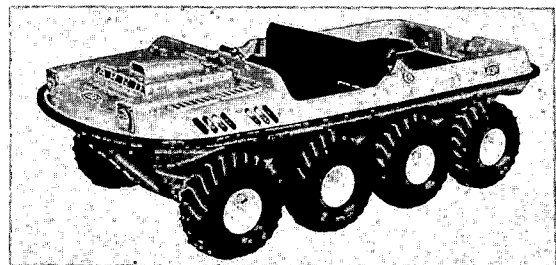
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Research Division Staff

The Research Division is housed in an apartment building amid tall cypress trees sporting native orchids in Lauderhill, Florida. Squirrels, ducks, and a wide variety of other birds contribute to the bucolic atmosphere. However, the small converted apartment that serves as an office for the Division is more functional than decorative. Sophisticated business equipment rests on well-used secondhand furniture. Filing cabinets are everywhere. Stacks of cardboard boxes reach to the ceiling and piles of papers, reprints, and computer printouts cover every available square inch of shelf space.

The Research Division performs a wide variety of duties involved with the Foundation's overall commitment to research toward improved care and an eventual cure for paraplegia.

Each member of the small staff wears several hats and performs a multitude of tasks. A key individual is Administrative Assistant Marcia Williams, who recently celebrated her fifth anniversary with the Foundation. Marcia's duties range from opening mail and answering the telephone to editing highly technical publications and maintaining the Division's accounts.

Research/Data Assistant Jeanette James has primary responsibility for maintaining computer listings of scientists and scientific publications. For this purpose, she uses equipment in the Data Processing Department of Encore Service Systems in Boca Raton and operates the small computer system in the office—primarily for recording receipts and searching national databases for current scientific information. During

her initial training under the CETA program, Jeanette completed several courses in math, computer logic, and programming.

Research Director Rich Veraa was a mechanical engineer until an auto accident left him quadriplegic in 1965. The accident understandably turned his interests toward neurological science and central nervous system regeneration. Subsequently he pursued graduate studies in physiology at the University of Illinois and the University of Miami and served as a Board member and Vice President of the Foundation. Since establishment of the Research Division in 1975, Rich has directed the Division and worked to maintain liaison between the Board and officers of the Foundation, the Central Office, and the Scientific Advisory Committee.

Specifically, Rich has responsibility for developing research programs and implementing them in close coordination with the Executive Director. Rich writes technical publications and works with the Central Office in developing promotional and informational materials. He handles technical correspondence and responds to inquiries for information on research matters. In addition to managing the Division,

continued on page 33



Richard P. Veraa



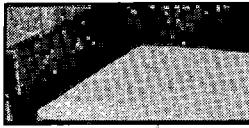
Marcia Williams



Jeanette James



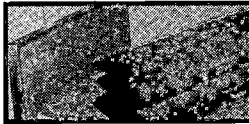
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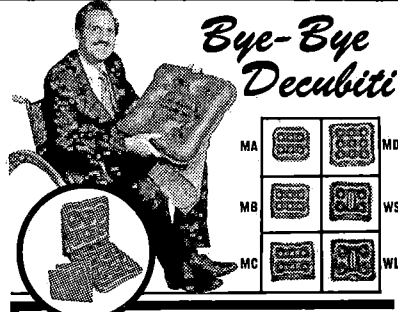
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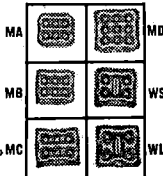
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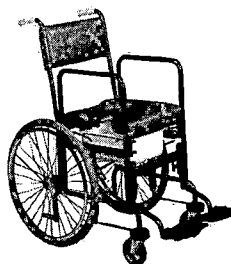
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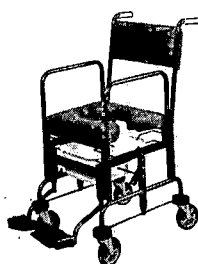
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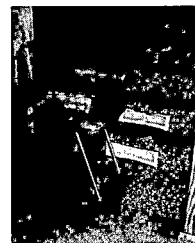
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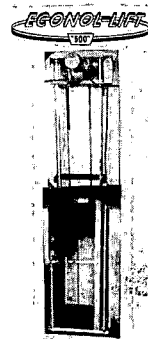
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Research Staff from page 31

Rich monitors the enormous volume of scientific literature, screening articles for relevance to central nervous system regeneration and inclusion in the Foundation's database.

Literature-screening is a never-ending process in the Research Division. As publications relevant to central nervous system regeneration in spinal cord injury are identified, they are entered in the computer, and reprints of the articles are obtained for the files.

From January through the end of May the Research Division is occupied with the Foundation's Fellowship Program. First, application forms are mailed to 2,000 scientists in 50 countries. Then, as the April 1 deadline nears, packages are received containing applications and supporting documents — ranging from 70-100 pages each. These are duplicated, packaged, and sent to each member of the Scientific Advisory Committee for review and evaluation. The next step is tabulating written ballots returned from the Committee. Numerical ratings are averaged, and the best-rated applicants are funded according to resources available for this purpose in each given year.

A new program to provide funding for research project grants is expected to be established this year. The application and evaluation procedures will be essentially similar to those of the Fellowship Program, but the annual time schedule will be arranged so as to keep the staff busy (or busier) during the summer and fall months.

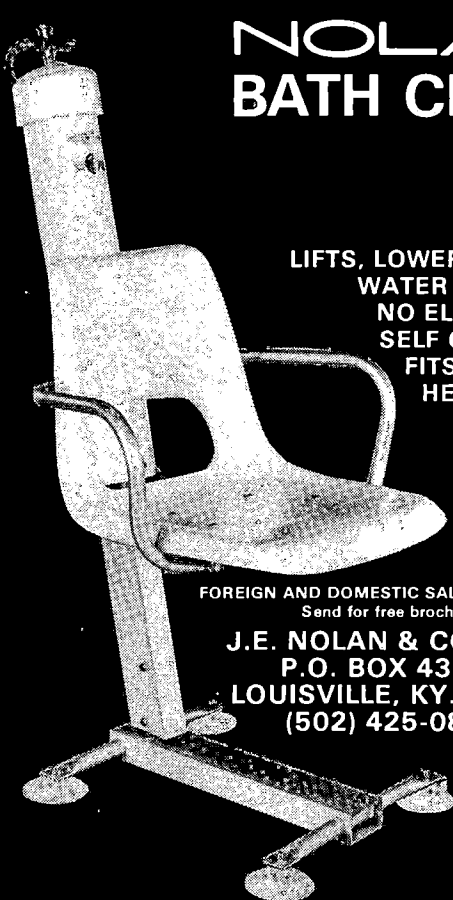
Another "seasonal" activity is administration of the Foundation's series of international scientific conferences. This process begins with planning and submission of grant proposals a year ahead of time. There is a frenzied burst of activity as the conference date approaches — duplicating and binding abstracts, finalizing hotel and travel arrangements, making last-minute changes, printing programs, and attending to the multitude of other details involved in management of such major meetings.

For the Research Division staff, the most substantive work begins after the conference with the writing of the formal report of proceedings for publication in an international scientific journal — traditionally *Experimental Neurology*. This actually is a year's work involving transcribing 40 hours of presentations and discussion from audio and video tape, summarizing individual presentations, and sending the summaries to the presentors for additions, corrections, and reference citations. The refined information is then assembled into a cohesive draft, which is rewritten and edited in close consultation between Rich Veraa and Bernice Grafstein, chairperson of the Scientific Advisory Committee. The two confer by mail and phone until — after several revisions — the final review article emerges.

During this process Marcia Williams — in addition to typing the drafts and manuscripts — continually monitors grammar, syntax, and accuracy and keeps track of cited references. This is a tedious and exacting part of scientific writing that often goes unrecognized. With 271 references to be listed by number in alphabetical order and cited by number, it becomes a major undertaking to add or delete references — especially in a nearly-final draft — as is often necessary.

Other functions of the Research Division include arranging the program for research sessions at the Foundation's annual conventions and providing articles for the *Convention Journal* and *Paraplegia Life*. In short, the Research Division staff performs a wide variety of functions in support of the Foundation's research goals and stands ready to serve the members of the Foundation, spinal cord injured persons everywhere, and the scientific community at any time. □


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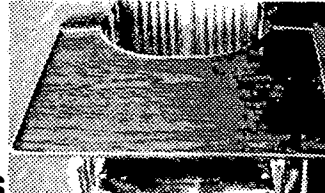



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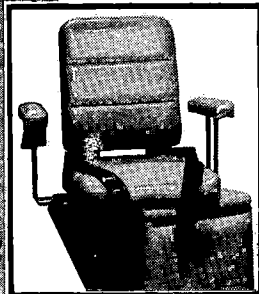
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Designer Genes Take Dominant Position in Fellowship Awards

Now in its fifth year, the National Spinal Cord Injury Foundation Postdoctoral Research Fellowship Program continues to support the work of outstanding and innovative young scientists.

Jordan Fellowship: J. H. Pate Skene

The recipient of the Jordan Research Fellowship is J. H. Pate Skene, 26, currently pursuing postdoctoral studies in neurobiology at Stanford University. Skene received his B.A. in molecular biology at Vanderbilt University in 1974 and his Ph.D. in neural science and molecular biology at Washington University in St. Louis in 1980.

One of the most crucial questions in nerve regeneration is why some nerve cells can regenerate or grow new fibers — such as those in the central nervous system of fish and amphibia and the peripheral nerves in mammals — while other nerve cells do not have this ability — such as those in the central nervous system of adult mammals including human beings. Skene has discovered a class of proteins, designated "growth associated proteins," which he has shown are produced in the neurons of both amphibia and mammals when they regenerate their axons. These proteins do not appear to be present in nonregenerating mammalian neurons. Thus, an understanding of the action and genetic expression of these proteins will almost surely provide an important key to the question of why some neurons regenerate and others do not.

As a Jordan Fellow, Skene will be working in the laboratory of John A. Freeman in the Department of Anatomy at Vanderbilt University. This laboratory is well-equipped for the new technologies of recombinant DNA research, and staff there have experience with this type of work. During his fellowship period, Skene will be making (designing) recombinant DNA clones corresponding to the messenger RNA's for growth associated protein from toad central neurons, which can regenerate their axons. With these molecular clones, it will be possible to apply the powerful and expanding techniques of molecular biology to achieving a detailed view of the regulation of genes associated with successful axon regeneration and to understand how the organization and regulation of these genes differs between regenerating and nonregenerating neurons.

North Shore Chapter Fellowship: Steven Green

The recipient of the Foundation's North Shore Chapter (Long Island) Fellowship is Steven Green, 27, presently at the California Institute of Technology in Pasadena. Green received his B.S. degree from the University of Wisconsin in 1975 and his Ph.D. in genetics and neurology from CalTech in 1981.

Like Skene, he will be applying the techniques of genetic engineering to the question of central nervous system regen-

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Vivian Schiff, President of the North Shore Chapter (Long Island), presents a \$15,000 check to Bob Moss, Senior Vice President of the Foundation. The money was raised by the Chapter and will be used for a Foundation research fellowship in spinal cord regeneration. —Photo courtesy of Long Island Trust Company

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Designer Genes from page 35

eration. However, the context will be different. Green will study the effects of proteins produced outside the neuron that stimulate growth: specifically, nerve growth factor. In genetic studies, it is important to be able to produce large numbers of identical cells for study and manipulation without uncontrollable genetic differences. In recombinant studies (such as Skene's) this is accomplished by inserting small fragments of genetic material into rapidly-proliferating bacteria, permitting the study of many copies of the particular gene and its products. For studies of phenomena on a larger scale, such as axon formation and growth, it would be useful if clones of neurons were available. Unfortunately, the adult neuron cannot divide and proliferate, so this is impossible.

However, Lloyd A. Greene in the Department of Pharmacology at New York University Medical Center, in whose laboratory Steven Green will be working, has developed a line or clone of tumor cells (designated PC12) derived from a type of tumor of the nervous system the cells of which resemble immature neurons. When nerve growth factor is added to PC12 cells, they stop dividing, grow fibers, and acquire all the chemical and morphological properties of normal adult nerve cells. Since these cells, unlike neurons, can proliferate in culture, genetic methods can be used.

Among Steven Green's experiments will be isolation and analysis of mutant lines of PC12 cells that fail to form fibers in response to nerve growth factor. Genetic, morphological, and biochemical studies will be done, comparing these mutant cells with "normal" PC12 cells as well as truly normal neurons. These will identify cell components involved in axon growth and show how they interact. Morphological studies will focus on the fibrous proteins that already are known to be involved in the control of cell shape and movement and that almost certainly are involved in axon growth as well.

We express our deepest appreciation to the members and friends of the Foundation's North Shore Chapter (Long Island) for making this fellowship possible.

Foundation Fellowship: David C. Kuo

A Foundation research fellowship also goes to David C. Kuo, 31, of Rutgers Medical School. Kuo received his B.A. degree from Carleton College in Minnesota in 1973, his M.S. in neuroscience from the University of Florida in 1976, and his Ph.D. in neuroscience from Rutgers University.

It is well-known that bladder-emptying in humans, as well as in various animals, is abolished during the period immediately following injury of the spinal cord. Bladder function then is slowly recovered over a period of weeks or months, finally reaching the so-called "automatic" or "reflex" state. Kuo intends to use electrophysiological and neural anatomical techniques to examine the mechanism underlying the recovery of bladder function after spinal transection in cats. William C. deGroat of the Department of Pharmacology at the University of Pittsburgh Medical School, in whose laboratory Kuo will be working, has indicated that the reflexes that operate the automatic bladder function in spinal cord injured individuals involve nerve pathways that are fundamentally different from those that activate the bladder in neurologically intact persons. It is, however, still completely unknown whether this reflex is a "new" mechanism that emerges through the reorganization and perhaps new growth in the nervous system following an injury or whether it represents the re-activation of a previously-existing infantile reflex that had previously been inhibited by central control from the brain.

Kuo will approach this problem using electrophysiological and neuroanatomical techniques that he feels will provide

important new information about regeneration in central autonomic pathways and about the factors involved in disruption and partial recovery of bladder function in spinal cord injured persons. He will also use immunohistochemical and pharmacological techniques in an attempt to identify the chemical neurotransmitters in these pathways. In addition to basic information regarding the reaction to injury and recovery in nervous systems that these studies will provide, Kuo hopes that his research will provide direction for new therapeutic approaches to improve bladder function in spinal cord injured persons and possibly facilitate the diagnosis and treatment of other neurogenic bladder disorders as well.

Foundation Fellowships Fill the Gap

It should be noted that much has been said—and certainly will be said during the convention—about the possible effects of present and proposed government fiscal constraints on the future of regeneration research. At this writing, the medical sciences as a whole have fared reasonably well. The exception—and this applies to all the sciences—is that funds for training and subsequent career development of young scientists have been severely curtailed.

Many concerned scientists have expressed opinions that might be summarized as follows: "I'm all right, but where are our new scientists going to come from?"

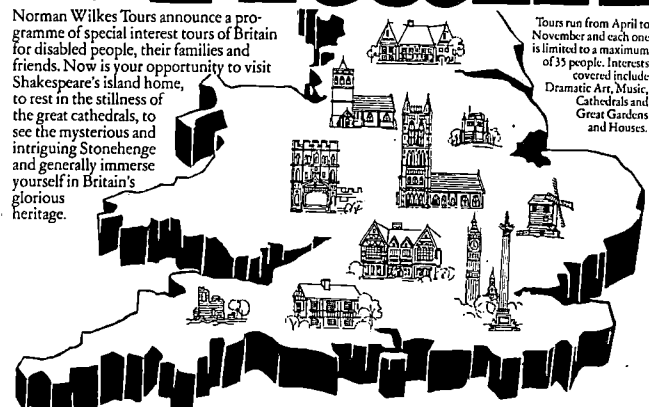
In this light, the Foundation's Postdoctoral Research Fellowship Program assumes extreme importance, for if the present trends continue, it may be only through our efforts and those of other private agencies that young scientists have the opportunity to demonstrate their capabilities and establish themselves professionally in fields related to regeneration research. □

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New Approaches to the Problem of Regeneration in the Central Nervous System

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by Bernice Grafstein

My purpose here is to describe the kinds of approaches that are being taken in trying to make some advance on the problem of central nervous system regeneration. There are a number of very basic things that we have to keep in mind—and when I say “we” I mean not only my fellow scientists and I, but also you as people who are intimately concerned with this problem on a personal level.

First of all, let us consider what is meant by regeneration. Regeneration in terms of regrowth or replacement of cells and tissues of the body happens all the time—in the skin, in the liver, in many other tissues. What makes the nervous system special is that it cannot replace itself by producing new cells. We are born with almost all the nerve cells we are ever going to have. A few nerve cells are produced after birth, usually very small ones, but in general the main structure of the nervous system is already laid down at the time we are born. And when a nerve cell subsequently dies, it is not replaced. That is one important aspect of the nervous system that we have to keep in mind.

The other very important aspect is that, again unlike most other tissues of the body, the nervous system has very specific connections among its cells. This is not true of a tissue like the liver or the skin, in which the mass of cells functions regardless of how the individual cells are arranged. But in the

nervous system, correct function depends on the nerve cells' finding their correct neighbors to connect with and interact with. Therefore, the problem of central nervous system regeneration is, to begin with, not a problem of getting nerve cells to replace themselves. What we are concerned with first of all is that in the case of impaired nerve cells with parts that have been cut off, we should be able to simulate the cells to grow those parts again, like the branches of a tree, so that they may be able to produce new connections with other nerve cells. That is one of our basic goals. The other basic goal, probably even further off, is to ensure that those connections are the correct ones.

At the present time we are trying as well as we can to find answers for both of these problems, and I would like to give you a very brief survey of what is being done and the general theories that are being adopted.

Now first of all, let me introduce you to the nerve cell. The cell body is the center of chemical activity in the cell. For example, the nerve cells that control your arms and legs have their cell bodies in the spinal cord, and they have branches distributed all through the spinal cord on which other nerve cells make contact. Each cell has one long branch, called the axon, that makes contact at its terminals with either muscle cells or gland cells, or, within the central nervous system, with other nerve cells. Bundles of such axons form the nerves of your arms and legs, for example. (See figure 1.)

If the nerve cell body is damaged, the whole nerve cell disappears, since the cell body is the center of life for the nerve cell, producing most of the materials that keep the nerve cell alive. Proteins and fats are mostly produced here and then are sent out by a process of transport along the various branches including the axon—this is what keeps the axon terminals alive.

What Happens to the Nerve Cell During Regeneration?

When an axon is damaged, the part of the axon that is removed from the cell body (and therefore deprived of all the materials that are being produced there) dies. In some cases this axon can be replaced because the axon puts out a new branch (or in a few cases, more than one branch), which grows out in the general direction that it occupied before. This process of regrowth of the axon involves a series of very

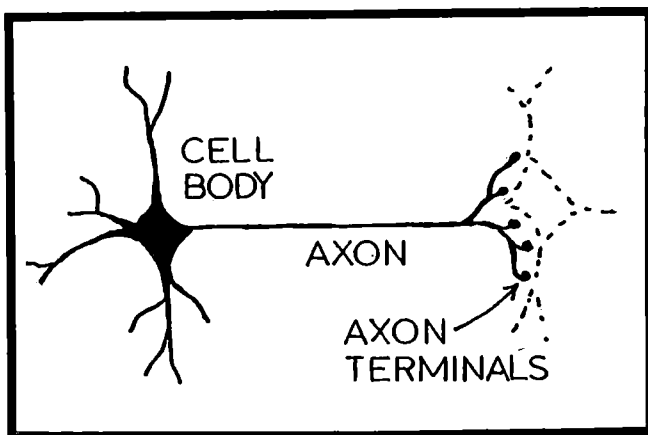


Figure 1. The Parts of a Normal Neuron in Relation to the Neuron with Which It Connects

Bernice Grafstein is professor of physiology at Cornell University Medical College and chairperson of the National Spinal Cord Injury Foundation Scientific Advisory Committee.

important changes at the axon tip. First of all, a large bulb is formed at the cut end of the axon, and the critical question for regeneration is whether the bulb is going to stay like this—in some cases, it stays like this indefinitely—or whether this bulb is going to reorganize itself to become like that organism that perhaps many of you are familiar with from elementary biology classes: the amoeba. The amoeba puts out “feet” (pseudopods), by means of which it pulls itself along. In the same way, the tip of the axon will begin to put out pseudopods, which enable it to probe its way: the protoplasm of the tip flows out and then withdraws and then flows out again, gradually elongating. What is happening at the axon tip is therefore extremely important for the process of regeneration, and some of the work that is now being done on regeneration concentrates particularly on these events. (See figure 2.)

A nerve cell that is regenerating, however, is undergoing changes not only at the tip of the axon where the outgrowth is occurring, but all over. The reason for this is that the material

that the axon tip requires for its growth is being produced back in the cell body. The materials originating in the cell body are transported along the axon until they reach the axon tip, where they are used to produce the new length of axon; conversely, the production of materials by the cell body is influenced by what is going on at the axon tip. We do not yet know how the cell body can be aware of what is going on at the axon tip, since the cell body may be as much as several feet away from the tip. Nevertheless, it is clear that very dramatic changes can occur in the nerve cell body. For example, the cell body may become enormously enlarged, and its internal structure may be very much disturbed. Also, its chemical reactions may be very much altered from normal. So we must consider a relationship between two partners: on the one hand there is the axon tip, which requires materials from the cell body in order to regenerate; on the other hand, there is the cell body, which supplies materials to the axon tip and which is altered because of conditions at the axon tip.

The Role of the Nerve Cell Body in Regeneration

How does the production of materials by the cell body change during regeneration? Which of these changes are necessary for regeneration? Among the changes that happen in nerve cells when they begin to regenerate is a decrease in the production of materials that are required by the nerve cell for communicating with other nerve cells. As long as that axon is disconnected from other nerve cells it is not going to be able to carry out its functions appropriately, and therefore the materials necessary for this kind of communication are not critical at that stage in the nerve cell's life. The decrease in materials required for communication presumably makes possible an increase in the production of structural materials.

For studying problems like these, we must be prepared to consider any kind of nerve cell that can regenerate. We are therefore interested not only in nerve cells in the spinal cord, but also in those that run outside the brain and spinal cord to all the parts of the body. We are also interested in nerve cells in animals that, for reasons that are not clear yet, have the capacity for regeneration in the brain and spinal cord. In fact, much of the work in my own laboratory is done in the visual system of fish, because those nerve cells regenerate remark-

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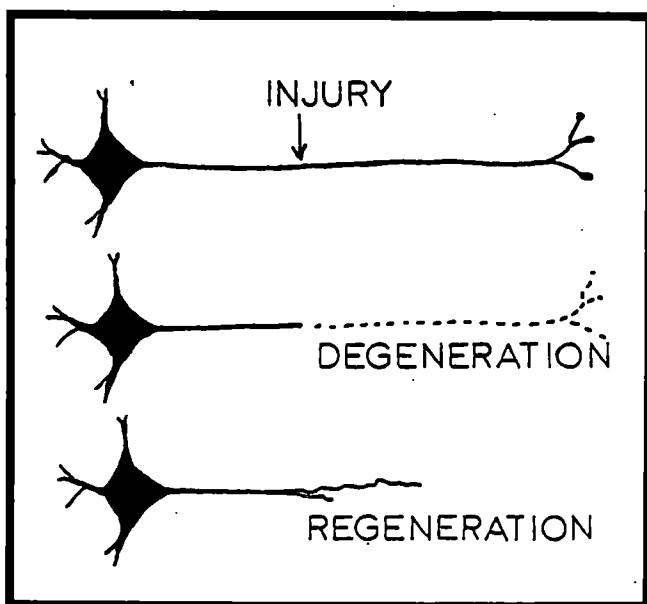


Figure 2. Sequence of Events in Normal Regeneration of an Axon

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CONTENTS: List of Figures and Tables. Preface. Acknowledgments. PART I — SPINAL CORD INJURY AND THE REHABILITATION PROCESS. 1. The Consequences of Spinal Cord Injury. 2.

Rehabilitation as a Behavior Change Process. PART II — ADJUSTMENT TO SPINAL CORD INJURY: THE STATE OF THE ART. 3. Psychological Factors in the Adjustment to Spinal Cord Injury. 4. Social Factors in the Adjustment to Spinal Cord Injury. Variables Associated with Productivity Following Spinal Cord Injury. 6. Sexuality and Spinal Cord Injury. 7. The Effect of the Treatment Environment on Adjustment to Spinal Cord Injury. 8. Therapeutic Techniques. 9. Adjustment to Spinal Cord Injury: An Overview. PART III — FUTURE DIRECTIONS. 10. Research Issues and Methodologies. 11. An Expanded View of Rehabilitation. Bibliography. Index. About the Authors.

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ably well. Not only do these cells produce new axons; in addition, the new axons are able to find their way to correct connections in the brain. We know that if you cut the optic nerve in a fish, after about a month it will begin to see again. Obviously there are some very remarkable things going on there, and we want to find out what those things are.

Another important problem is: if certain materials are necessary or important in regeneration, how can we stimulate the production of those materials? This also is one of the problems that I am personally very much concerned with. I am looking for agents that will somehow increase the synthesis of proteins and fats, or will increase the metabolic response of the nerve cell to injury. Such agents are very limited in number so far, but they are important: not only do they stimulate regeneration and therefore might they be able to initiate regeneration in cells that do not normally regenerate, but in addition, they can tell us something about the process of stimulation and thereby lead us to other more practical ways of causing it. Thus, although our ultimate objective is to stimu-

kinds of nerve cells in the body, and these still remain to be discovered.

Another experimental technique that we have found useful in stimulating regeneration is previous injury. If you measure the rate at which an axon grows out after it has been cut, you find that it may grow out a lot faster if the nerve cell has been injured previously. This tells us that something the first injury did has prepared the nerve cell for better outgrowth. Obviously, this is not a technique that one can apply in a clinical situation, but in the laboratory it can tell us something about the kinds of events in the nerve cell that control the rate of outgrowth.

The Relationship Between the Nerve Cell Body and the Axon Tip

Until now, I have been concentrating on the nerve cell body: what it does in connection with regeneration and how you might improve what it does. The nerve cell body, however, is just one of the participants in the relationship that determines whether or not regeneration will occur. The other is the axon

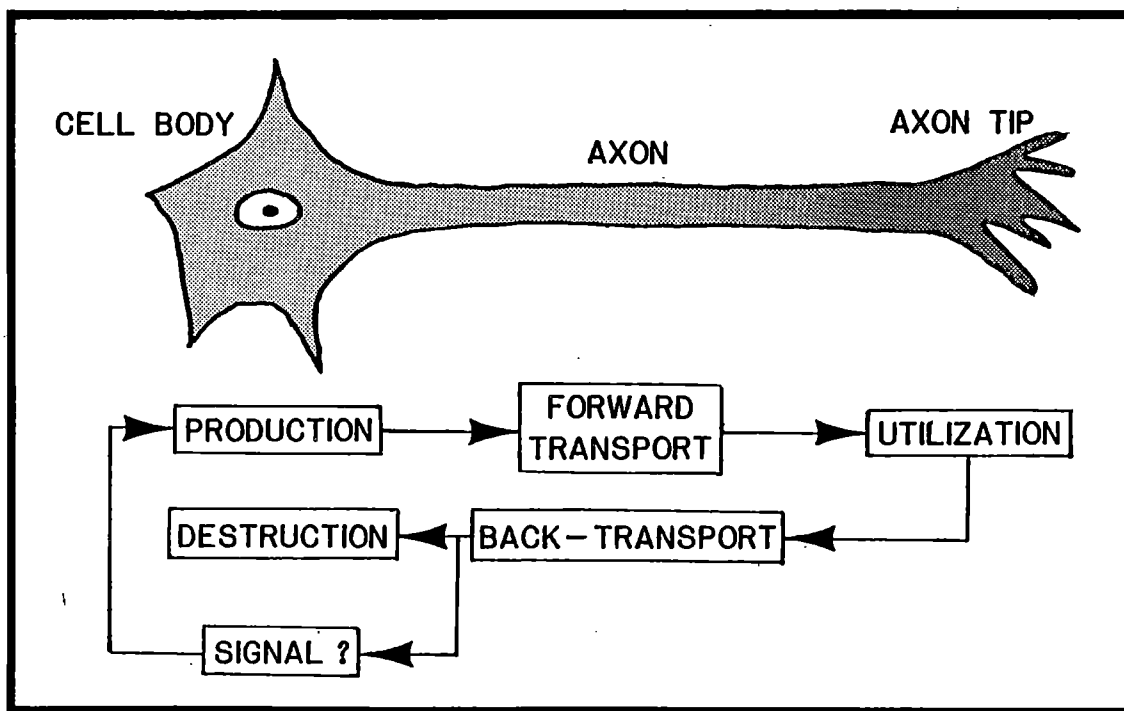


Figure 3. Movement of Materials (Axonal Transport) in a Regenerating Neuron

late regeneration in nerve cells of the human spinal cord that normally do not regenerate, one of our strategies is to look for things that will improve regeneration in cells that do regenerate. It is possible to use regenerating nerve cells in lower animals as a kind of assay system, to find out whether various things will stimulate regeneration or not.

One substance that is known to enhance the chemical activity of some kinds of nerve cells and to cause them to grow more rapidly is called nerve growth factor. This material was discovered about 20 years ago by Rita Levi-Montalcini at Washington University in St. Louis. This is now a very well-characterized material, commonly obtained for experimental purposes from the salivary glands of mice. The only difficulty about nerve growth factor is that it really works on only a very limited group of cells, such as those that control the blood vessels of the body. In these cells it is taken up by the tip of the axon and then sent back along the axon to the cell body. It stimulates the cell body to produce more material of the kind that is necessary for growth of the cell. We suspect that there may be a whole group of such materials acting on different

tip, and one of the very important things that we still have a lot to find out about is how the nerve cell body communicates with the axon tip and vice versa. One thing we know is that there is a two-way movement of materials between them. Materials produced by the cell body are sent down to the axon tip where at least some of them are utilized. Those that are not utilized may be returned to the cell body, where they are either destroyed or reused. This two-way communication system may also be important in other ways. For example, it may be important in signalling to the cell body whether the axon is intact and functioning normally or whether it has been injured. We think that when an axon has been injured the material that comes back from the axon is not entirely normal. For one thing, the axon is shorter, and therefore materials that are coming from the cell body and normally go all the way down the axon will turn around and come back to the cell body earlier than they should. This early return may provide a signal to the cell body to change its production of materials. (See figure 3.)

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Another important factor is that normally the nerve cell takes in a certain amount of material at its axon tip. For example, nerve growth factor enters the nerve cell through the axon tip and then is carried back to the cell body, where it stimulates the production of new materials. There may well be other important substances that enter the nerve cell in this way, and it is likely that when the axon is cut the kinds of materials that reach the cell body are quite abnormal. For example, the blood proteins that are always present throughout the body normally do not penetrate into the nerve cell, but if the axon is damaged, they may enter through the cut axon tip and be carried back to the cell body.

It is evident that the process we call axonal transport—the movement of materials from the cell body along the axon to the axon tip, and in the reverse direction, from the axon tip back to the cell body—is extremely important for the understanding and analysis of nervous system regeneration. In exploring this process, we look wherever we can. We look in humans: it is possible to apply some of these techniques now in clinical situations to study what passes along the nerves. We look in all kinds of experimental animals, like snails and leeches. Some of the nerve cells in these animals are extremely large and therefore offer the opportunity to study what goes on in a single nerve cell. Tracer materials can be injected directly into such a cell, and we can then study how they become distributed through the cell and how the cell reacts to them. This is a very important area of investigation in connection with general problems of how a nerve cell keeps itself alive, but it is obviously also very important with respect to the problem of how regeneration occurs and what factors may affect it.

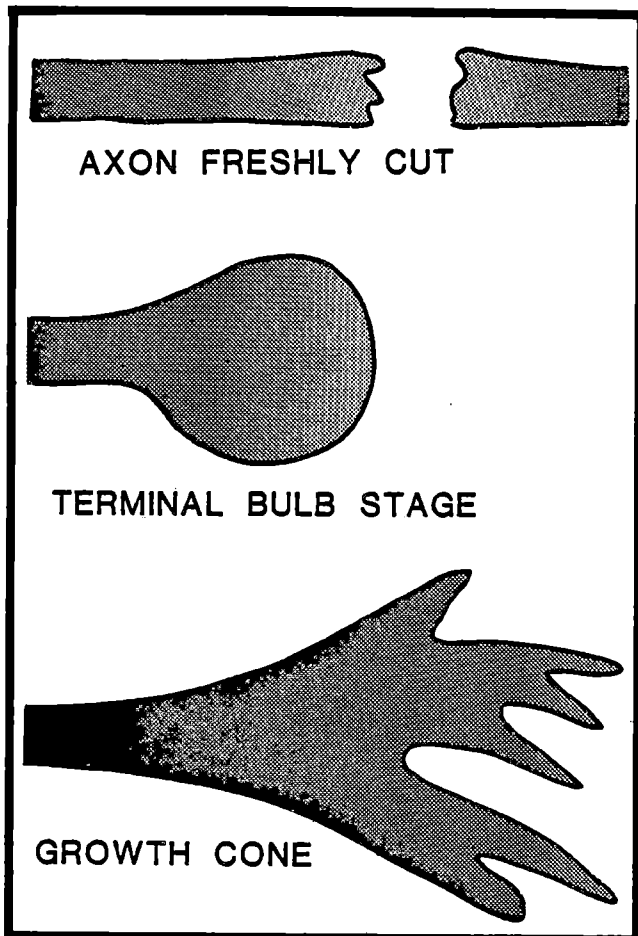


Figure 4. Events at the Tip of a Cut Axon That Lead to Regeneration

Properties of the Growing Axon Tip

Whatever the nerve cell body may do in terms of the production of materials, whatever the axon may do in moving those materials along, ultimately what we have to be concerned about is how materials are going to contribute to the outgrowth of the axon. When an axon has been cut, first its tip swells, due to the continual arrival of materials originating in the cell body. Then the tip forms a "growth cone," which intermittently advances and retreats, with movements resembling those of the single-celled amoeba. (See figure 4.)

An important means of studying these kinds of processes has been the tissue culture preparation. You can take a small piece of the nervous system, particularly from a young animal, and have it grow in a dish, or at least stay alive, for weeks and even months. In that case, many of the nerve cells will put out new axons. Since the amount of nervous tissue is so small and since it grows out in a very thin layer, individual nerve cells and individual growth cones can be observed as they grow. Much of what we know about the growth cones' properties has been found out in tissue culture. Also, many studies of growing axons have been made in developing animals, since in a young animal, with its nervous system not entirely connected up yet, a lot of growth will be going on.

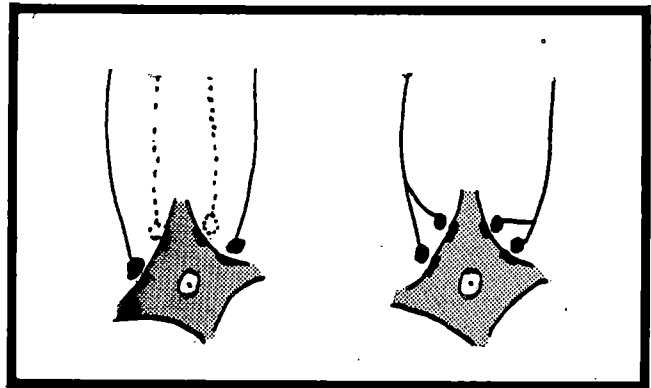


Figure 5. Collateral Sprouting of Intact Axons (Solid Lines) Following Injury and Degeneration of Nearby Axons (Broken Lines)

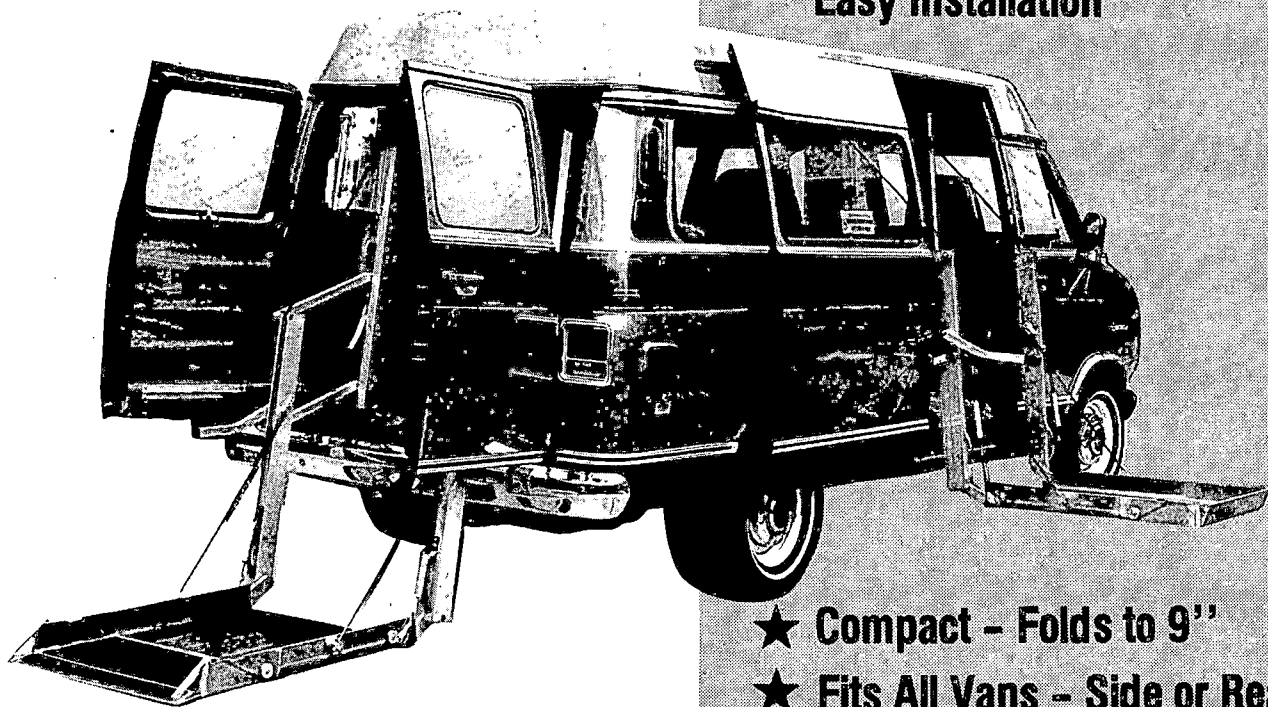
Control of Axonal Sprouting, Rate of Outgrowth, and Establishment of Connections

There is one kind of nerve growth that can occur in quite mature animals, and even in the central nervous system. This kind of growth occurs in neurons that are adjacent to an injured region. Suppose, for example, that in a group of four axons coming down from the brain into the spinal cord, two are injured and degenerate. The remaining two somehow are able to sense that there has been some injury in the neighborhood, and they can sprout—putting out branches that make connections in places that had previously been occupied by the axons that had been injured. This process we call "collateral sprouting." It is not regeneration in the usual sense, because it is not the injured neurons but the adjacent intact ones that are growing. Thus, although the cells of the mature central nervous system—the mature spinal cord, for example—may not have great powers of regeneration, those nerve cells can sprout and can grow, even if normally they only do so under special circumstances. (See figure 5.)

This kind of collateral sprouting has been subjected to considerable scrutiny in the last few years, and we are just beginning to understand the circumstances in which it occurs. One possibility is that chemicals that encourage sprout-

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ing are released by cells that are dying as a result of the injury. Another very interesting possibility is that nerve cells may normally produce growth-inhibiting chemicals. These chemicals may be constantly released from the ends of axons and prevent adjacent axons from sprouting. This conceivably might be one of the reasons the human central nervous system does not regenerate well. Yet another possibility is that when some neurons are injured they are not able to activate the nervous system in a normal way, and this may affect the regenerative ability of that region. We do know that chemicals that interfere with activity, such as local anesthetics, seem to have the ability to promote axonal outgrowth to some extent. We therefore have some very intriguing possibilities in connection with collateral sprouting that we are going to have to look into in the near future.

Beyond the question of what induces axons to sprout, we have to consider what factors control the rate of outgrowth and what factors determine whether the axon will reach its appropriate end target or not. These problems seem to center around the question of the relationship between the growth cone and its environment. The growth cone advances along the surfaces of the cells that it encounters as it grows. The physical and chemical properties of these surfaces are very important in determining how fast that growth cone can move. Various studies are being done, therefore, to analyze the properties of these surfaces and to determine how you might change them in order to improve the outgrowth. The kinds of chemicals that adjacent cells may be producing may also be important. For example, certain cells in the body that are intimately related with nerve cells produce nerve growth factor and thereby stimulate outgrowth of axons. Also, there may be some interactions similar to those in the immune system of the body, that is, involving a "lock-and-key" relationship between the surface of the growing axon and the surface of the cells it encounters.

One area that is becoming extremely important now, to which we have not given much consideration for perhaps 50 years, is the presence of "tropic" factors. These are chemicals that attract the growing axon and stimulate its growth in one direction rather than another. A very recent finding has been that nerve growth factor, in addition to being a trophic ("nourishing") factor, may be a tropic factor.

Finally, another area that is receiving increasing attention now is the elimination of incorrect connections. We know that during development incorrect connections in the central nervous system die off, although the mechanism involved is not clear. It is interesting that the idea of approaching the problem of regeneration by looking at things that interfere with or limit regeneration is now becoming an important strategy in this field.

In summarizing, I want to remind you of the "organism" we are dealing with: This is the nerve cell with its cell body where materials are produced; its axon along which materials are being sent in both directions; and the axon tip where outgrowth occurs, where utilization of the materials that are produced by the cell body occurs, and also where certain kinds of materials—trophic factors, other kinds of materials—can be taken up directly from the neuron's environment and shipped back to the cell body. Therefore, when a nerve cell is injured and regeneration occurs (or unfortunately does not occur) it is not just a question of what the injury has done at a particular point, for example, at the axon tip, but rather what has happened throughout the whole nerve cell. The study of the whole nerve cell is, therefore, what we are interested in at the present time. □

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Independent Living Programs in the United States Today

by Mary L. Widmer, Lex Frieden, and Laurel Richards

Mary L. Widmer is a research analyst at ILRU. She supervises the collection, organization, and dissemination of information on the state of the art in the independent living movement. She has been involved in programs concerned with improving the quality of life for spinal cord injured persons since 1973.

Lex Frieden is director of the ILRU project and assistant professor of rehabilitation at Baylor College of Medicine.

Frieden has been involved in the independent living movement since he was spinal cord injured in 1967.

Laurel Richards is training and materials development coordinator for the ILRU project. She designs curricula for project training conferences and supervises development of publications and training materials.

The Independent Living Research Utilization (ILRU) Project in Houston has been documenting the growth and development of the independent living movement since its beginning.¹ There have been dramatic changes in the field during the past decade. The purpose of this article is to examine some of the data collected by ILRU and stored in its national data bank and to assess the status of the independent living movement as exemplified by the characteristics of programs across the nation.

Independent living as a programmatic concept is clearly still in the process of evolution. New programs are started every day, and old programs face the possibility of cutbacks in services and staff. The number of independent living organizations has grown from barely a handful to over 100 in six years. The total investment in programs and services has grown from about one-half a million dollars nationally in 1974 to more than eighteen million dollars nationally in 1980. The number of disabled persons served has grown from about 500 in 1974 to more than 8,000 in 1980.

In the early 1970s, spinal cord injured persons were the principal focus of three "pioneer" programs: the Center for Independent Living in Berkeley, the Boston Center for Independent Living, and Cooperative Living in Houston. In fact, the latter two served individuals with spinal cord injuries almost exclusively.

Since then, the notion that barriers to full independence can more effectively be eliminated when all disability groups work for each other's interests has gained widespread acceptance among individuals active in the independent living movement. Services are being extended to a variety of disability groups, though persons with mobility impairments are still the most frequently served. It is no longer unusual to find programs serving persons with deafness, brain injury, visual impairment, mental retardation, mental illness, and stroke, as well as persons with mobility impairments.

Today, even though many programs have been "opened

up" to serve all disability groups, spinal cord injured persons are still primary recipients of independent living services. Over two-thirds of the programs surveyed by ILRU staff identified individuals with spinal cord injuries as a specific focus of service.

Classification of Programs

It is difficult to say what type of program is typical. The field is still new, and each program varies in one or more ways from other programs. However, in 1978, the ILRU Project at The Institute for Rehabilitation and Research (TIIR) in Houston undertook the task of developing a system for categorizing programs that provide services designed to facilitate independent living for disabled persons. With input from experts in the field of independent living, definitions were established.² Three basic types of independent living programs (ILPs) were identified: the independent living center, the independent living residential program and the independent living transitional program. In addition to these, there are miscellaneous organizations that provide independent living services as an incidental or secondary part of their overall programs. These organizations were designated independent living service providers.

Independent Living Centers—An independent living center (ILC) is controlled by the consumers it serves (either 50% of the board of directors or 50% of the staff is handicapped). It is community-based and nonprofit. It is nonresidential but provides a listing of accessible housing. It either has an attendant registry or provides attendants directly. It offers peer counseling and either paralegal or financial counseling. It conducts some sort of organized advocacy. The center's primary purpose is to provide an ongoing support system for its clients where they live, rather than a short-term program that teaches a specific set of independent living skills.

Independent Living Residential Programs—Unlike the center, an independent living residential program (ILRP) exists

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TYPE OF PROGRAM: ILC
DISABILITY SERVED: MANY
TARGET DISABILITY TYPE: SCI,MR,BL,DF,AG,CP,AMP,MI,ST,ETC
NO. PERSONS SERVED/YR.: 500+
GOAL ORIENTATION: ONGOING
SERVICE SETTING: BOTH RESIDENTIAL AND NON-RESIDENTIAL
NEIGHBORHOOD: URB RESIDENTIAL
SERVICE DELIVERY METHOD: BOTH DIRECT AND INDIRECT
SERVICE DELIVERY STYLE: CONSUMER
VOCATIONAL EMPHASIS: INCIDENTAL

SPECIFIC SERVICES:
* INDICATES A PRIMARY FOCUS

*APARTMENT REGISTRY
*ATTENDANT SERVICES
*ATTENDANT REGISTRY
*TRANSPORTATION
VEHICLE MODIFICATION
*PARA-LEGAL
*PEER-COUNSELING
FAMILY COUNSELING
MEDICAL TREATMENT SERVICE
*COMMUNITY CONSULTING AND ADVISING
*POLITICAL LOBBYING AND ORGANIZING
*ADVOCACY

*SOCIAL/RECREATIONAL
*RESEARCH
*COMMUNICATIONS
*INFORMATION EXCHANGE REGISTRY
HOUSEKEEPING
FINANCIAL AID OR COUNSELING
*INDEPENDENT LIVING SKILLS TRAINING
*WHEELCHAIR OR EQUIPMENT REPAIR
*VOCATIONAL EDUCATIONAL COUNSELING
*VOCATIONAL TRAINING
*VOCATIONAL PLACEMENT
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Figure 1. Profile of an Independent Living Center (ILC) from the "Registry of Independent Living Programs"

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PHONE: (207) 767-2189
*****

TYPE OF PROGRAM: ILTP
DISABILITY SERVED: MANY
TARGET DISABILITY TYPE: SCI,CP,AMP,MS,MD,POLIO ADULTS
NO. PERSONS SERVED/YR.: 0-25
GOAL ORIENTATION: TRANSITIONAL
SERVICE SETTING: BOTH RESIDENTIAL AND NON-RESIDENTIAL
NEIGHBORHOOD: URB CENTRAL BUS DIST
SERVICE DELIVERY METHOD: BOTH DIRECT AND INDIRECT
SERVICE DELIVERY STYLE: CONSUMER
VOCATIONAL EMPHASIS: INCIDENTAL

SPECIFIC SERVICES:
* INDICATES A PRIMARY FOCUS

*RESIDENTIAL
APARTMENT REGISTRY
ATTENDANT SERVICES
ATTENDANT REGISTRY
VEHICLE MODIFICATION
*PEER-COUNSELING
FAMILY COUNSELING
*COMMUNITY CONSULTING AND ADVISING
POLITICAL LOBBYING AND ORGANIZING

*ADVOCACY
*COMMUNICATIONS
*INFORMATION EXCHANGE REGISTRY
*FINANCIAL AID OR COUNSELING
*INDEPENDENT LIVING SKILLS TRAINING
*VOCATIONAL EDUCATIONAL COUNSELING
*VOCATIONAL TRAINING

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Figure 2. Profile of an Independent Living Transitional Program (ILTP) from the "Registry of Independent Living Programs"

primarily to provide an alternative to living in an institution or with parents or other relatives. In addition to housing, it provides or coordinates attendant services and transportation services. It may also provide peer counseling services or opportunities for development of self-help networks.

Independent Living Transitional Programs — An independent living transitional program (ILTP) is designed to help severely disabled individuals move from a level of relative dependence to a level of relative independence. While its primary service is provision of independent living skills training, it may also provide housing, information registries, and other independent-living-related services.

Independent Living Service Providers — An independent living service provider (ILSP) either does not meet the criteria for classification as one of the three types of ILPs or is engaged in some activity that may foster client dependence: for example, protective supervision, medical treatment, or maintenance of a sheltered workshop. The ILSP does, however, offer a small number of discrete independent living services for handicapped people. Although access to a small number of services may be adequate for a disabled person in some instances, maximal independence in day-to-day activities requires a more holistic independent living program that provides assistance in a variety of essential areas: for example, transportation, accessible housing, attendant services, peer counseling, and independent living news updates (for new products, laws, services, areas of advocacy, etc.).

Characteristics of Programs

Research by ILRU project staff indicates that the three primary types of ILPs have several important features in common. First, at least 30% of the staff is handicapped or at least 50% of the board of directors is handicapped—that is, the programs involve people from their client populations in many substantial ways. Program consumers may be managers, advisors, line staff workers, etc.

Second, at least two of the following services are provided: transportation, peer counseling, political advocacy or organizing and lobbying, social and recreational activities, independent living skills training, and wheelchair and other repair. Providing a variety of services in accordance with individual consumer resources and needs gives the independent living program the ability to furnish comprehensive services to severely disabled people.

Third, neither medical treatment, protective supervision, nor maintenance of a sheltered workshop is a primary purpose of the organization. Although these may be necessary and valuable services in some instances, they are based on a treatment-oriented model in which severely disabled people are not required or even expected to take an active role in directing their lives. Moreover, this model often leads to inappropriate placement of severely disabled individuals in segregated settings.

It is apparent that one important factor in determining

continued on page 49



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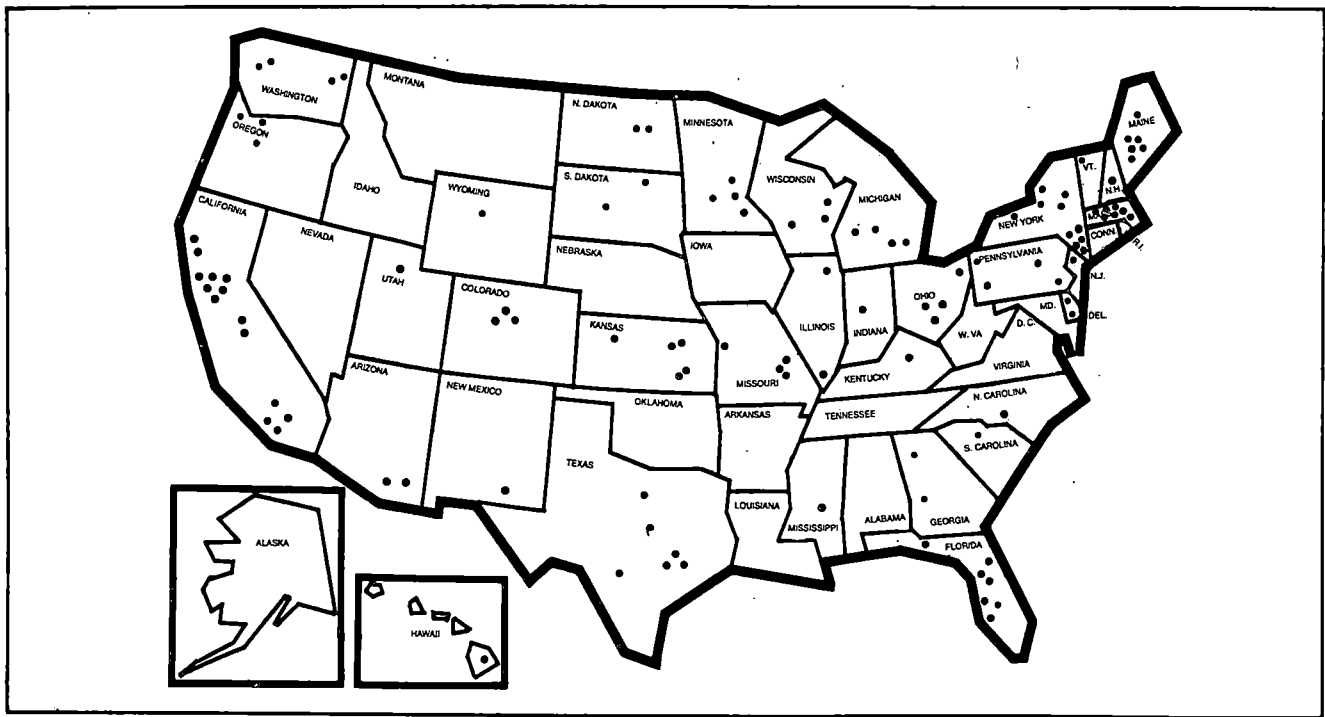


Figure 3. Map Showing Locations of Independent Living Programs (ILPs) in the United States

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whether an organization is really an ILP or simply an ILSP is the amount of consumer involvement in decision-making and service delivery. Another important factor is whether or not the client has access to a significant array of services that facilitate independent living. Since services that encourage dependent living contradict the underlying premise of the independent living philosophy, any organization that has as one of its primary purposes either medical treatment, protective supervision, or maintenance of a sheltered workshop is not considered an independent living program—even though it may provide some independent living services.

The Registry and the Directory

ILRU project staff have surveyed more than 110 independent living organizations during the past three years.³ Data are compiled in a computer printout called the *Registry of Independent Living Programs*. As shown in Figures 1 and 2, the *Registry* contains a variety of information about each program, including disability groups served, service delivery style and method, neighborhood setting, types of services provided for clients, and so forth. Also available is the *Directory of Independent Living Programs*, which lists the name, address, telephone number, and contact person for each organization. Both the *Registry* and the *Directory* are updated continually to reflect changes, deletions, or additions in the data base.⁴

The *Registry* is useful to disabled persons planning trips, vacations, or permanent moves and to counselors serving severely disabled individuals. It may also be of value to independent living program administrators who contemplate expanding services or relocating their facilities or who wish to compare their programs with other programs. The *Registry* is a comprehensive resource for all organizations that serve disabled persons.

Analysis of Survey Data

In addition to providing the basis for the *Registry* and the

Directory, data gathered from ILRU surveys is maintained in a computerized data bank on independent living programs. The data are used periodically to summarize information about the status of the independent living movement.

For instance, ILPs identified by ILRU surveys are marked on a map of the United States in Figure 3. The map shows that the largest groupings of programs are on the West Coast and the East Coast. There are fewer programs in the North and Southwest. In general, there are program clusters in states where vocational rehabilitation agencies have provided exceptional leadership and assistance in program development and where well-organized consumer groups have been able to initiate service programs. States where rapid development has occurred include Texas, Florida, Michigan, Massachusetts, and California. Figure 4 illustrates the proliferation of ILPs from 1970 to 1980.

Figure 5 illustrates another form of analysis based on ILRU survey data. It shows differences between the two most frequently occurring types of independent living organizations: the ILC and the ILSP. These two types of organizations make up over 90% of the organizations in the ILRU data base.

The data clearly indicate that a disabled individual who wishes to participate to the fullest extent possible in the normal day-to-day activities of life is much more likely to achieve this goal if an ILC is located nearby than if only a few services are available in the area where he or she lives. For example, 73% of the centers provide both direct services dispensed by staff at the center (for example, vehicle modification, peer counseling, and independent skills training) and referral services (for example, listing of personal care attendants, accessible housing units, and advocacy organizations). Only 43% of the independent living service programs have this capacity in their service menu. In addition, 93% of the centers have a peer and/or self-help style of service delivery (rather than nonhandicapped specialists delivering services) as compared to only 47% of the ILSPs. There is an even greater difference (100% of the ILCs; 41% of the ILSPs) with respect to

continued on page 51



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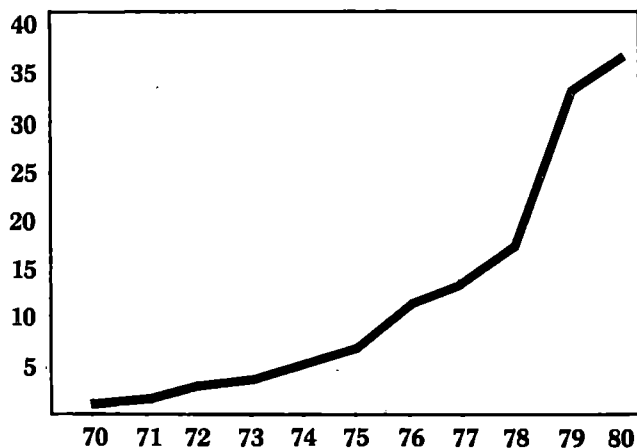


Figure 4. Increase in the Number of Independent Living Programs (ILPs) from 1970 Through 1980

This does not include approximately 50 new programs funded under Title VII, Part B, of the 1979 amendments to the Rehabilitation Act. These programs are being established now.

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provision of peer counselors, which is a major thrust of the independent living movement.

Another area of importance in the growth of the movement is advocacy. Again, the data in Figure 5 show clearly that the ILC more often coordinates this service than the ILSP. Thus, the ILC helps to bring people together who support the independent living movement and who are interested in making

	ILCs	ILSPs
Both direct services and referral lists available	73%	43%
Accessible apartments registry provided	97%	34%
Attendant registry (or service) provided	97%	51%
Peer and/or self-help style service delivery	93%	47%
Peer-counseling provided	100%	41%
Outlet for advocacy	100%	66%
Political lobbying group available	70%	27%
Paralegal services provided	50%	10%
Information exchange notices available	93%	29%
Newsletter type communications provided	73%	43%
Research is conducted	50%	25%
Financial aid and/or counseling provided	90%	53%

Figure 5. Comparison of Services Offered by Independent Living Centers (ILCs) and Independent Living Service Providers (ILSPs)

their needs and rights known to the general public. Closely connected with this focus are paralegal services, provided by 50% of the ILCs but by only 10% of the ILSPs.

Information exchange and newsletters may or may not contain advocacy-related materials, but they are essential for handicapped individuals who intend to continue to grow in their ability to live independently. Over three times as many ILCs provide this service as do ILSPs.

Two other differences between ILCs and ILSPs concern research (conducted at 50% of the ILCs but at only 25% of the ILSPs) and financial aid or counseling in financial matters (provided by 90% of the ILCs but by only 53% of the ILSPs). All of these data emphasize the holistic nature of the ILC and its capability to provide the disabled person with a variety of services necessary to enhance his or her level of independent living.

Future Concerns: Cutbacks and Closures

As a result of the 1980 elections, there is much speculation about how the expected reduction in federal support will affect the independent living movement. There are reasons to believe that some independent living programs may be unable to continue to offer the quality and quantity of services to which their disabled clients have become accustomed. Also, there is grave concern that reduced federal funding may cause a decline in the number of new independent living programs chartered.

According to Max Starkloff, chairperson of the ad hoc National Coalition of Independent Living Programs, "The current Reagan Administration proposals put more than 100 programs in extreme jeopardy of closure. This would force . . . thousands of severely disabled persons back into costly, ineffective, inhumane, institutionalized settings." ILRU survey research substantiates this statement. Support for independent living programs comes primarily from federal and state sources. If funding from these sources is withdrawn or severely diminished, many disabled people who now have relatively independent lifestyles may be forced to abandon them.

Independent living holds great promise for all people, but especially for the disabled people in our society. In order to help solve some of our major economic and social problems, society must assimilate disabled people into the community, meet their needs in an ordinary way, stop regarding them as a problem, and see them as the asset that they can be. There will be no need for costly categorical programs and separate facilities when severely disabled persons are able to participate as fully as possible as members of society. The nation would benefit from a healthy social and economic relationship between its nondisabled and disabled citizens. □

References

¹ The ILRU Project is a national resource center for independent living. Its goal is to improve the spread and utilization of results of research programs and demonstration projects in the field of independent living. Project staff serve independent living programs, consumer organizations, rehabilitation agencies, other providers of rehabilitation services, educational institutions, medical facilities, and other organizations active in the field, both nationally and internationally. ILRU was established in 1977 by the Rehabilitation Services Administration and is now sponsored in part by the National Institute of Handicapped Research, U.S. Department of Education. Future funding is being sought from foundations and other private sources.

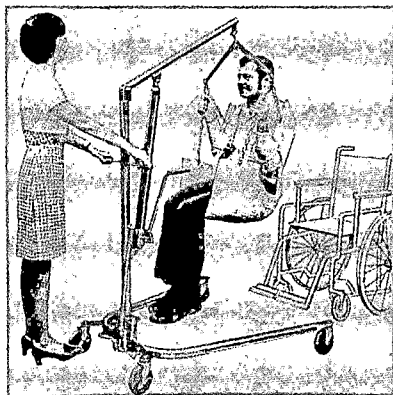
ILRU is open to the public. Project staff will respond to any request for information on independent living, preferably by mail. Write ILRU Project, The Institute for Rehabilitation and Research, P.O. Box 20095, Houston, Texas 77025.

² A copy of the *Glossary for Independent Living* and a list of the members of the ILRU National Advisory Committee are available from the address above.

³ Not yet surveyed are approximately 50 of the 76 ILPs that were awarded grants under Title VII, Part B, of the 1978 amendments to the Rehabilitation Act. As soon as these recently-established programs move out of the setup and early operational stages, they will be surveyed and added to the *Registry*. Almost all of the Part B-funded ILPs are styled after the center model and offer services to a wide variety of disability groups.

⁴ The *Registry* (\$10) and the *Directory* (\$5) also are available from the address above. Prepayment should accompany orders. Allow up to four weeks for delivery.

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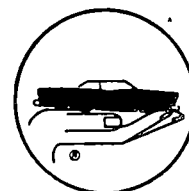


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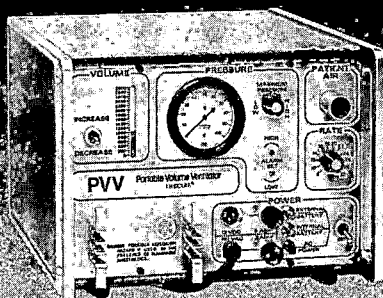
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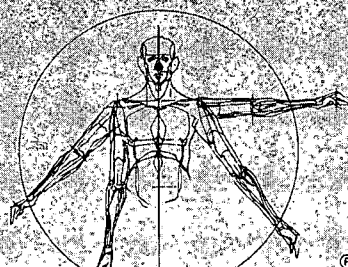
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Some Thoughts on the Care and Keeping of Attendants

by Nancy K. Smith

Most formal and informal discussions about personal care attendants (PCAs) to date have focused the "blame" for their high turnover rate either upon the lack of funds allocated to pay PCA salaries or upon the seemingly less-than-ideal type of person who has been attracted to personal care work.

The results of a 1980 study of 56 former and current attendants in the Madison, Wisconsin area,* however, suggest that there is no single reason why PCAs quit their jobs or find the jobs unfulfilling. While low pay was repeatedly mentioned by the subjects as a negative aspect of the job, it was not necessarily the sole reason for the high PCA turnover rate. Obviously, a major improvement in the job quality of the PCA would be to increase his/her salary. The attendants, however, recognized that that might not be possible and suggested other actions and attitudes they felt could be initiated by disabled employers, rehabilitation agencies, and potential attendants to make PCA work more pleasant and, thus, to encourage longer PCA employment tenure.

Since the entire concept of independent living is based upon consumer direction, the attendants in the Wisconsin study felt that if disabled consumers were responsible enough to hire and direct their own PCAs, they should also be responsible enough to try to resolve some of their employees' job complaints. The PCAs felt that rather than continuing to dwell on the problem of attendant turnover as something totally beyond their control, disabled employers and rehabilitation professionals could more effectively channel their energies into making job-quality improvements. Since the problems of PCA hiring and management will probably remain with severely disabled consumers for their entire lives, it seems advantageous to accept the recommended approach and to begin to explore some realistic options for improving the situation, even if there are no total solutions.

Suggestions for Employers

Probably the most important job-quality recommendation emerging from the Wisconsin study was insightfully summarized by a PCA who urged disabled employers to "make attendant jobs seem as important as they are when one is being hired." Many of the subjects felt that more people would be attracted to personal care work and would stay with it longer if they felt that what they were doing was not just manual labor, but a specialized, demanding job.

The aspects of their jobs that most of the attendants liked best were being able to help others and doing something worthwhile. The job aspects that the PCAs liked least were the lack of flexibility of working hours, no clear definition of duties

Nancy K. Smith is coordinator of disabled student services at the University of Wisconsin-Madison. She is a graduate of the University of Wisconsin-Milwaukee, with degrees in mass communication and rehabilitation counseling. This article is abstracted from her Master's thesis.

*Smith, N. *Personal Care Attendants: Keys to Living Independently*. Unpublished manuscript, 1980.

or written contract, lack of family cooperation, and failure of their employers to act as independently as possible. The two most frequently expressed frustrations of live-in attendants were not enough time off and lack of privacy. The attendants felt that employers could improve their PCAs' job quality by being more flexible in terms of hours worked in special circumstances, ensuring adequate privacy and time off for the live-in attendant, and offering more opportunity for independence and self-expression in the execution of duties, which would lessen the chance of the PCAs becoming bored with routine assignments. Most of the PCAs agreed that their jobs would be much more appealing if they could be given fringe benefits including days off, paid vacation days, and paid sick days, in addition to their salaries.

To lessen the chance of personality conflicts, the attendants stressed the importance of potential employers and employees taking the time to get better acquainted before the latter are hired. The PCAs said that their jobs were much more enjoyable when they had friendly relationships with their employers and there was mutual respect between employer and employee. The attendants also found it much easier, and preferred, to solve job-related problems by talking them over with their employers, if they had positive working relationships, instead of by simply resigning.

The characteristics/attitudes they look for in potential disabled employers were listed by the attendants, in order of importance, as:

- (1) Treating employees with kindness, fairness, and respect;
- (2) Knowing their own care needs;
- (3) Being able to offer both praise and criticism, when appropriate; and
- (4) Acting as independently as possible.

The attendants found it most difficult to work for employers who were overly demanding and rarely, if ever, showed appreciation for a job well done. They would also try to avoid an employment situation in which a disabled employer thinks that tasks can be done only one way and decides what the method must be. The attendants also warned potential PCAs to beware of the disabled employer who feels sorry for himself/herself, because he/she usually ends up taking out his/her frustrations on others, including attendants. In future job searches, the PCAs said that they would also try to avoid employers who try so hard to be nice to their employees that the employers' needs are often unstated and therefore unfulfilled. Another difficult "type" of disabled employer to work for, as rated by the attendants, is one who directly or indirectly tries to encourage pity from the PCA.

Suggestions for Rehabilitation Professionals

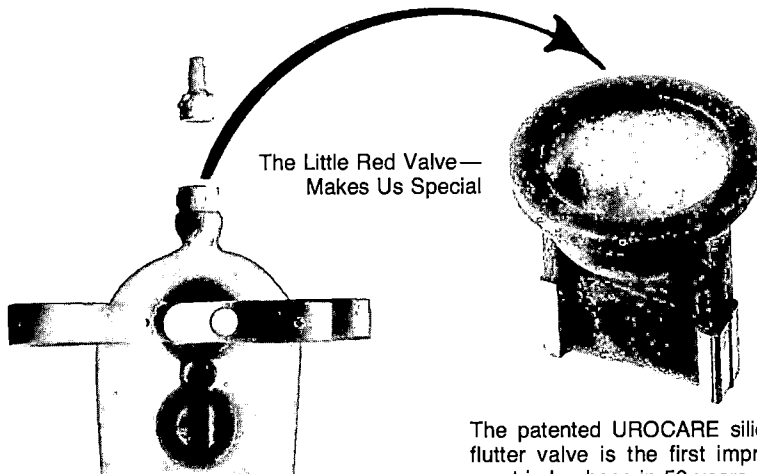
Several specific recommendations that could be implemented by rehabilitation professionals emerged from the Wisconsin study. First, 75% (42) of the subjects felt the need for more formal training before beginning PCA work. They

continued on page 55

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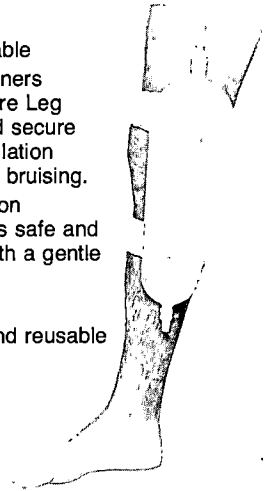
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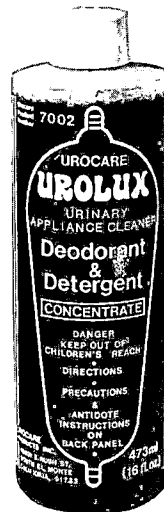
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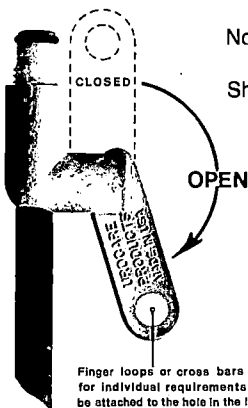
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Dissolves Crystal Build-Ups

- Cleans:
- Urinary Appliances
 - Plastic Valve Parts
 - Ostomy Pouches
 - Tubing
 - Urinals
 - Hydrocollators



LEVER OPERATED DRAIN VALVE



No Metal Parts
or
Sharp Corners

Finger loops or cross bars etc. for individual requirements can be attached to the hole in the lever.

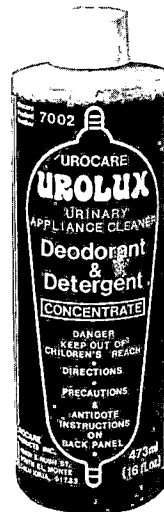
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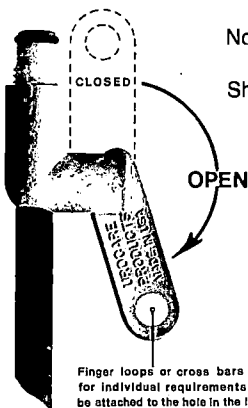
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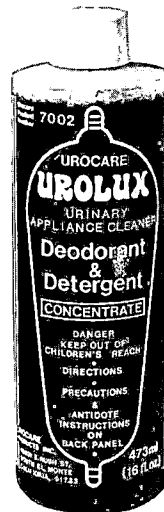
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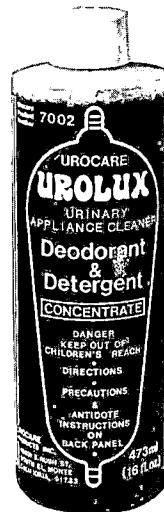
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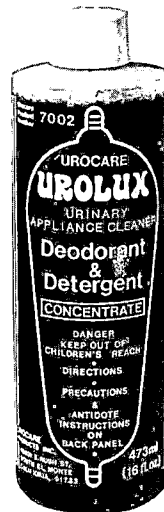
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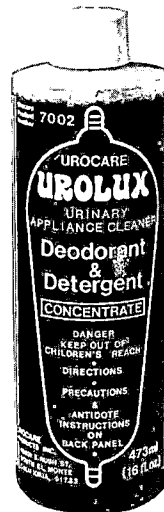
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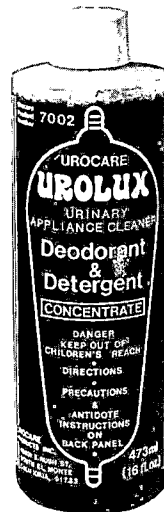
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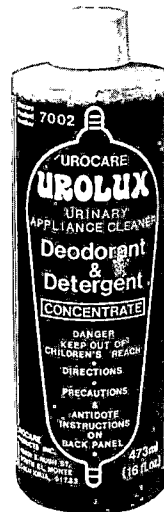
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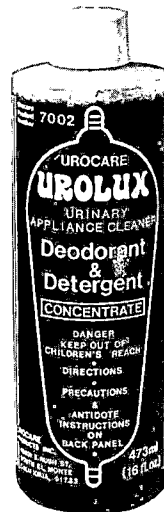
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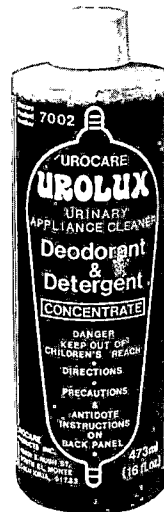
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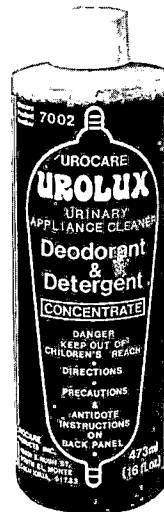
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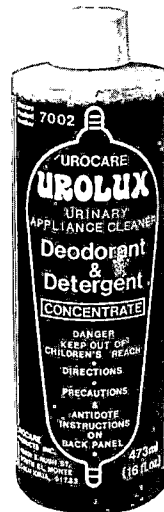
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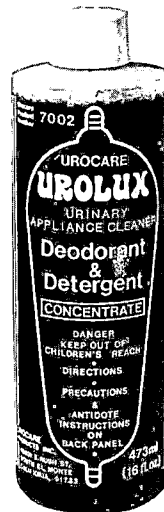
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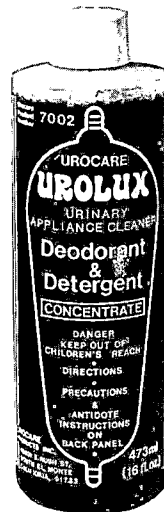
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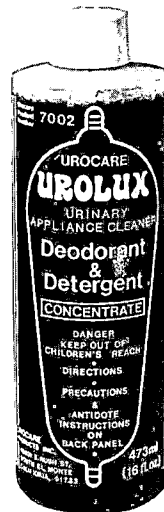
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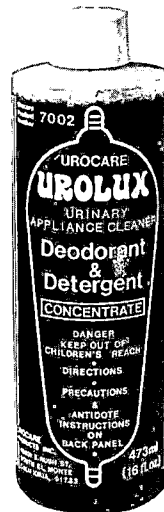
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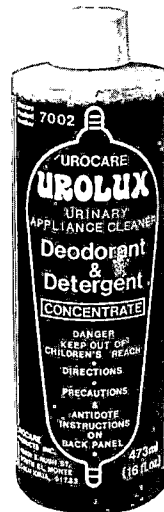
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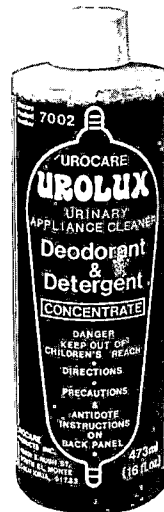
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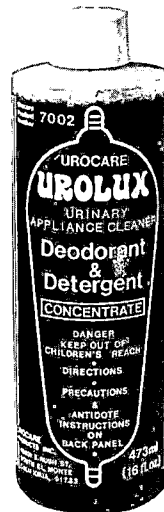
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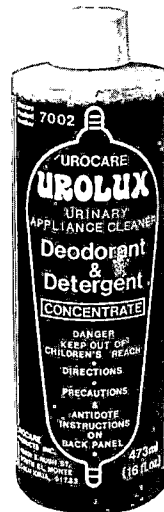
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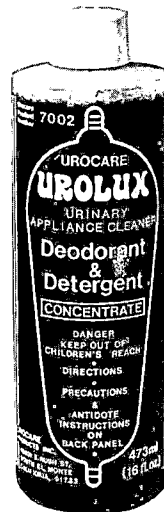
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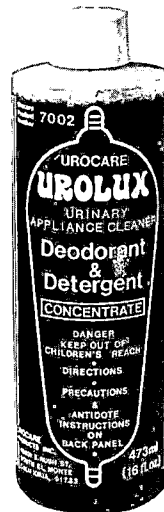
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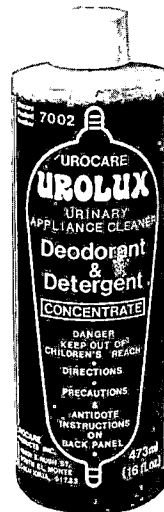
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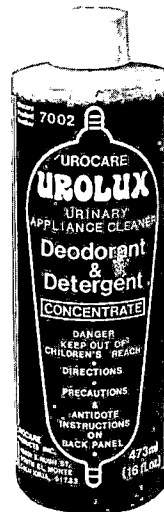
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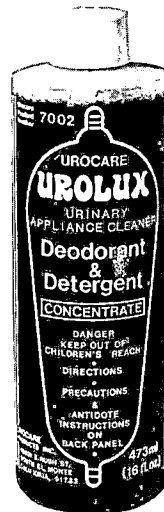
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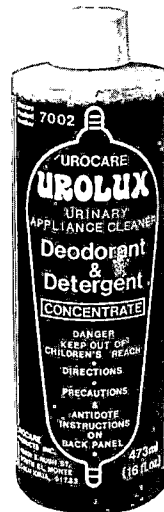
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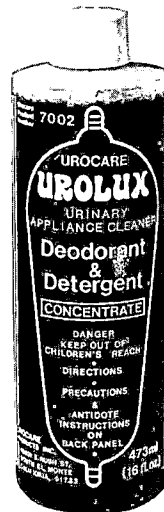
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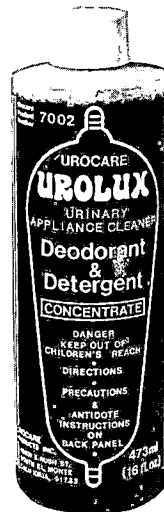
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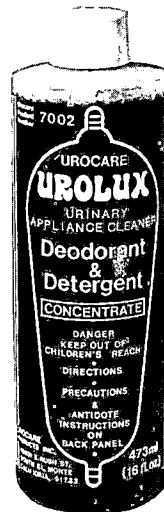
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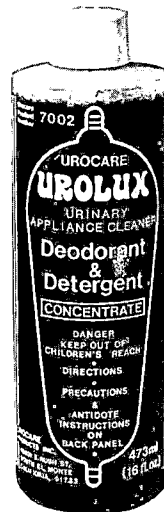
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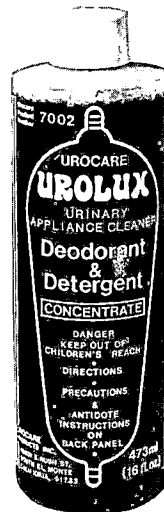
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Attendants from page 53

suggested that the following topics be included:

- (1) Techniques of bathing, grooming, toileting, dressing, feeding, transferring, and other specific skills;
- (2) Information on the psychological and physical aspects and implications of the specific disabilities of their future employers; and
- (3) Interpersonal relations and communication skills development.

Additional areas that might be included in an attendant training program are: the importance of maintaining the cleanliness of both the employer and his/her home environment; information on what to do in an emergency situation; information on community social and recreational activities available for disabled people; and development of self-preservation and coping skills for the PCA.

Second, 70% (39) of the Wisconsin subjects felt that it would be helpful if disabled people were given more training on how to be employers of PCAs. They suggested that the following topics be included:

- (1) Interpersonal and human relations skills development and assertiveness training;
- (2) How to be employers (i.e., how to interview potential PCAs, how to write clear job descriptions and employment contracts, how to make sure that duties are specifically defined and mutually understood before the PCA is hired, and how to inform potential PCAs about their salaries — the amount of payment, when they will be paid, the source of the funds, and any other relevant information — before hiring); and
- (3) Development of open, honest, and direct communication skills (how to express needs and instructions clearly, how and when to offer constructive praise and criticism, and how to supervise the attendant once he/she is hired).

Additional areas that might be included in an employer training program are: employer rights, how to be as independent as possible; awareness of medical and personal needs; and awareness of possible emergency care needs.

Third, 86% (48) of the Wisconsin attendants felt that their jobs could be improved by the availability of PCA support groups. The PCAs felt that if such groups were available for interested attendants, so that they could get together once or twice a month to discuss mutual problems and give each other support, it could help to ease their job frustration and lengthen the duration of their employment.

Fourth, the attendants thought their jobs would be more rewarding and appealing if rehabilitation agencies launched concerted public information campaigns to educate the pub-

lic about the concept of independent living and the importance of PCAs to disabled people. The attendants felt that a more positive image of PCA work would automatically attract more potential attendants and would help to keep those who are currently employed working longer.

Suggestions for Attendants

For the consideration of potential PCAs as well as disabled employers, the most important characteristics needed by good attendants were listed by the Wisconsin PCAs in the following order of importance: dependability/responsibility, patience, understanding/compassion (but not pity), and honesty. Other characteristics which seem to be helpful in PCA work, as seen by the people who do it, are flexibility, punctuality, and a sense of humor.

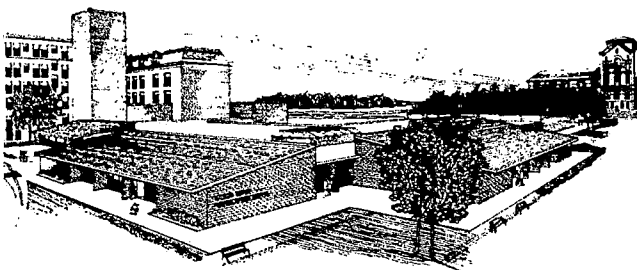
The subjects' major advice for potential attendants was to learn all the details of the PCA job description and then to agree upon and sign a written contract, before beginning employment. A PCA contract should include such items as pay, vacation, holidays, sick days, and/or other fringe benefits. Before the contract is signed, the employer and the attendant also should discuss how each envisions dealing with problems, should they arise.

Before they accept PCA positions, potential attendants should also be aware that many of the duties performed by a PCA do not directly involve personal care. In the Wisconsin study, for example, the two most-often-performed PCA tasks were housecleaning and cooking. Thus, if one has strong, negative feelings about cleaning, cooking, running errands, shopping, doing laundry, helping with correspondence, doing wheelchair maintenance, providing transportation, providing entertainment, doing yardwork, or similar tasks, he/she should seriously reconsider becoming involved in PCA work.

The subjects also urged potential attendants to check out their future working conditions in advance with regard to cleanliness, temperature, and smoking regulations. They should determine, before accepting employment, the length and number of breaks they will be allowed during the work day. As potential attendants consider PCA work, their predecessors urged them to be prepared for the time-and-responsibility commitment PCA work involves, to be prepared for low salaries and few fringe benefits, to recognize that their duties may be boring, to be sure to arrange to have sufficient time off, and to try to be prepared and willing to accept different lifestyles among their potential employers. □

This paper was supported in part by a training grant (#G008004103) from the U.S. Department of Education to the University of Wisconsin-Milwaukee.

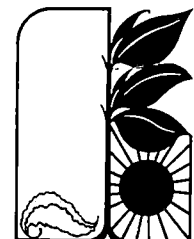
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Phone: (519) 662-2840
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Oregon Trail Chapter National Spinal Cord Injury Foundation

10138 N.E. Wasco Street
Portland, Oregon 97220
Phone: (503) 257-0706
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Paralyzed Veterans of America

4350 East West Highway, Suite 900
Washington, D.C. 20014
Phone: (301) 652-2135
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Paralyzed Veterans Association of Florida Inc.

136 S.E. 15th Street
Pompano Beach, Florida 33060
Phones: (305) 781-1243 or
781-4333
Page 30

Paraplegia Association of Rhode Island

120 Dudley Street, Suite LL5
Providence, Rhode Island 02905
Phone: (401) 331-4447
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Pergamon Press Inc.

Fairview Park
Elmsford, New York 10523
Phone: (914) 592-7700
Page 40

Raymo Products Inc.

212 South Blake
Olathe, Kansas 66061
Phone: (913) 782-1515
Page 33

REB Manufacturing Inc.

P.O. Box 276
Carey, Ohio 43316
Phone: (419) 396-7651
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Rehabilitation Institute of Chicago

345 East Superior Street
Chicago, Illinois 60611
Phone: (312) 649-6179
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Ricon Sales Inc.

11684 Tuxford Street
Sun Valley, California 91352
Phone: (213) 768-5890
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Sacred Heart Rehabilitation Hospital

1545 South Layton Boulevard
Milwaukee, Wisconsin 53215
Phone: (414) 383-4490
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Chester Schiff, P.E. Consulting Electrical Engineer

150 West 34th Street
New York, New York 10001
Phone: (212) 244-4745
Page 6

Sickroom Service Inc.

728 North 7th Street
Milwaukee, Wisconsin 53233
Phone: (414) 278-0606
Page 50

Charles B. Slack Inc.

6900 Grove Road
Thorofare, New Jersey 08086
Phone: (609) 848-1000
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George H. Snyder

5809 N.E. 21st Avenue
Fort Lauderdale, Florida 33308
Phones: (305) 781-1243 or 781-4333
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South Central Wisconsin Chapter National Spinal Cord Injury Foundation

Box 98
Walworth, Wisconsin 53184
Phone: (414) 275-3318
Page 20

St. Louis Ostomy & Medical Supply

11722 Manchester Road
St. Louis, Missouri 63131
Phones: toll free 1 (800) 325-0979 or
(314) 821-7355 (Missouri residents call
collect)
Page 48

Support Systems International Inc.

P.O. Box 570
Johns Island, South Carolina 29455
Phone: (803) 559-0391
Page 42

Tenax Corporation

4 Old Newtown Road
Danbury, Connecticut 06810
Phone: (203) 792-8400
Page 34

Thera-Plast Company Inc.

P.O. Box 341
Suffern, New York 10901
Phone: (914) 357-6154
Page 32

Twin Cities Chapter National Spinal Cord Injury Foundation

P.O. Box 8588
Minneapolis, Minnesota 55408
Phone: (612) 853-5241
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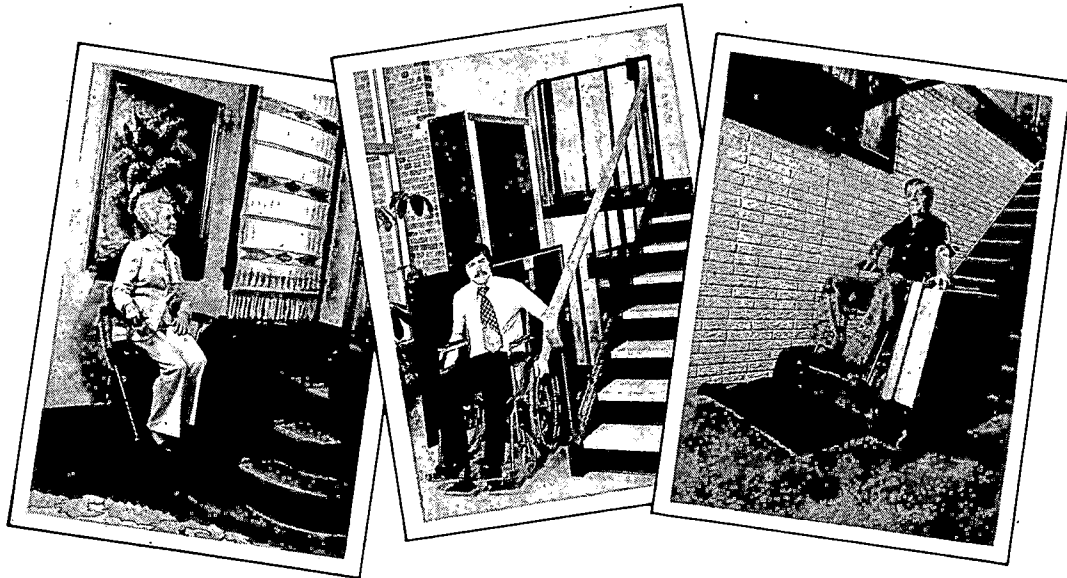
Urocare Products Inc.

10031 East Rush Street
South El Monte, California 91733
Phones: (213) 442-3477 or 442-3478
Page 54

Norman Wilkes Tours

c/o Flying Wheels Travel
143 West Bridge Street
Owatonna, Minnesota 55060
Phones: (507) 451-5005 or
toll free 1 (800) 772-9351
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Lots of people need help at some time or another. Not because they aren't self-sufficient. They are, at work, school, and at home enjoying their families. But many of them need help climbing stairs. And that's where the Cheney Company enters the picture.

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helping people help themselves

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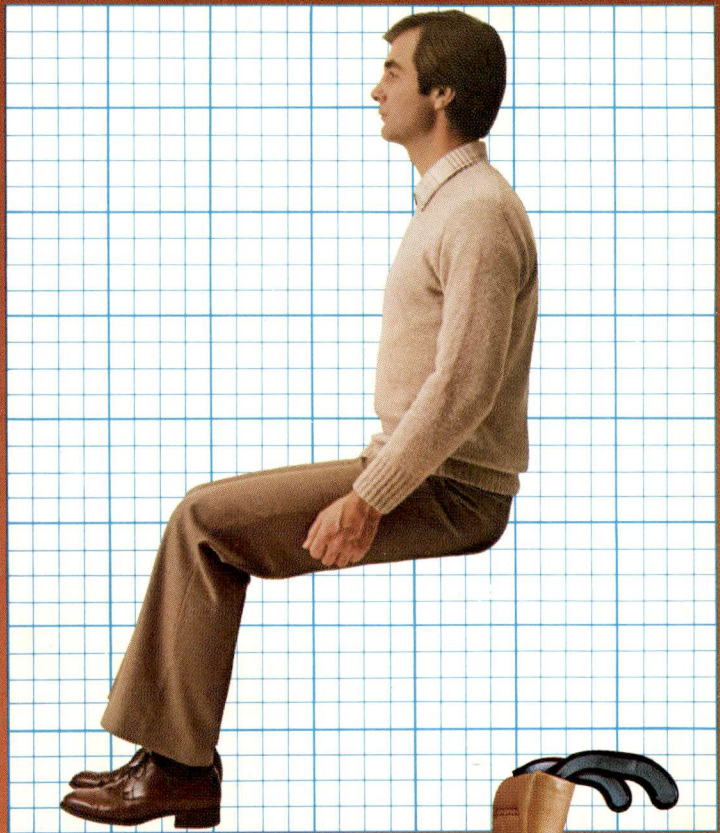
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