

Into the Stacks
Volume 2 Issue 2, April 2004

Commentary

by Mary Jo Dorsey

One of the advantages of being back in school is having access to seemingly unlimited information resources. For a librarian, this is seventh heaven! This semester, I was involved in my first teaching practicum, which is a requirement of all PhD students. Fittingly, I taught under the fine guidance of my mentor and advisor, Dr. Ellen Detlefsen, Associate Professor, School of Information Sciences. This semester, we ventured into the depths of Consumer Health Information.

What is Consumer Health Information? Well, have you ever Googled topics such as "Diabetes," or "Men's Health?" If you have, you were looking for health information for you or a loved one, the Consumer. In this course, we led graduate students in the School of Information Sciences through the delicate balances of 1) learning how to create or manage a patient/consumer health library; and 2) the various populations in society to whom specific information is targeted -- for example: ethnic groups, women, men, the elderly, teens . . . Health information is one of the most searched topics on the Internet. Finding the right information for your specific needs or concerns is vital if you are to be accurately informed. Throughout the semester, students evaluated books, journals, audiovisuals, media programs, websites, and a vast array of resources. One specific assignment that thrilled me was a small group project in which five students collaborated in creating a "Pathfinder," or list of resources for the topic of my choice. Wanting to tie in my school experiences with my workplace, I chose our world class Burn Unit as an area of concentration for information resources. My small group searched high and low for information resources for burn survivors. So, with that in mind, I take you to our quarterly feature, "A Pathfinder of Consumer Health Materials for Burn Survivors and their loved ones."

Congratulations and thanks to these students for their contribution to West Penn Hospital and for a job well done.

Feature

**Pathfinder for Burn Patients and their families At the Western Pennsylvania Burn Trauma Center
Pittsburgh, Pennsylvania**

Presented by
Joel Burkholder
Bridget Conlogue
Pam Ferkett
Clint Hall
Mary Marx

University of Pittsburgh, School of Information Science LIS 2585 April 12, 2004

Books:

Bridge Never Crossed – 170 pages - \$16.95

Author: Capt. George A. Burk

Publisher: Science & Humanities Press:

January, 1999

Available from the Phoenix Society,

<http://www.phoenix-society.org>

This story has been and will continue to be a true inspiration to anyone who reads it. The author was in a plane crash that has lingering effects that will be with him always. Yet he is one of the nicest, most genuine people and has a wonderfully positive outlook on life. His story gives encouragement and a new perspective in facing the challenges of living, despite tragic events.

Burn care and rehabilitation: principles and practice

Author: Richard, Reginald; Staley, Marlys

Publication: Philadelphia: F.A. Davis, 1994

"A comprehensive text-reference for students as well as therapists and therapist assistants with all levels of burn care experience. The text is divided into four sections. The Fundamentals includes a history of burn rehabilitation and covers the basic sciences as they relate to burn care. The Care focuses on resuscitation of the patient and care of the burn wound

itself. The Rehabilitation takes a comprehensive look at a multitude of therapeutic interventions, from patient evaluation through discharge and follow-up care. The Concerns addresses areas of burn care which either require special management principles or are less commonly encountered by therapists."

Burned and Beautiful - \$14.95

Author: Kathy Tartakoff

Publisher: Children's Legacy

Available from the Phoenix Society,

<http://www.phoenix-society.org>.

Burned-- now what? A self-help guide for the burn survivor and their family, written by a burn survivor

Author: Soulsby, William.

Publisher: Buy books on the Web.com, 2000

"Perhaps nothing ravages the body and spirit quite so fiercely as burns. Burns have no mercy. They can melt away skin, leaving scars that contract and deform the remaining tissue. They can destroy the eyelids, mouth, nose, ears, and even bone. Without a functional mouth, how does one eat? The purpose of this book is to provide knowledge, insight, and self-help to all of us that have suffered the intense and extremely painful experience of body burns. "You will never find a stronger-willed person than a burn survivor, for they have suffered the worst injury to the human body anyone can endure...and survive!"

Burns and blisters

Author: Silverstein, Alvin; Silverstein, Virginia B.; Nunn, Laura Silverstein.

Publisher: New York: Franklin Watts, 2002

From School Library Journal:

"Grade 4-6-Burns discusses the function of skin, what happens when burns or blisters damage it, types of injuries, their treatment, and why protection from the sun is important. The emphasis is on prevention. Joanna Cole's Cuts, Breaks, Bruises, and Burns (Crowell, 1985; o.p.) has a simpler explanation for the healing process."

Burns and blisters

Author: Royston, Angela.

Publisher: Chicago: Heinemann Library, 2004

Burns Sourcebook: Basic Consumer Health Information about Various Types of Burns and

Scalds, Including Flame, Heat, Cold, Electrical, Chemical, and Sun Burns (Health Reference Series) - \$78.00

Author: Cook, Allan R.

Publisher: Omnigraphics, Inc., 1999.

"Information is geared to general readers looking for information on types of burns, short- and long-term treatment options, prevention, and first aid. Chapters are arranged in sections on burn statistics, types of burns, treatment, rehabilitation, safety and prevention, and emergency procedures. Includes a glossary and a directory of resources for burn patients, plus b&w photos showing results of different treatment options."

Coping Strategies for Burn Survivors and Their Families - \$14.95

Authors: Norman R. Bernstein, Alan J. Breslau & Jean Ann Graham

Publisher: Praeger Publishers/Greenwood Press, 1988

Available from the Phoenix Society,

<http://www.phoenix-society.org>

"Coping Strategies provides the burn patient and his/her family a unique source of information and insight on the effects of disfigurement, sexuality, cosmetics, prosthetics, coping with stress, anxiety and guilt, and about employment strategies. These topics are addressed by professionals and survivors and parents of survivors--uniting all points of view and making this work important reading."

Emotional Care of the facially burned and disfigured

Author: Norman Bernstein

Publisher: Boston: Little, Brown, 1975

Healing Inside Too

Author: Scott, Rick.; Franklin, Jed.

Publication: Vancouver, British Columbia Kicking Horse Productions, 1990

"Jed Franklin was 8 years old when something happened in a flash. It changed his life. A gasoline generator exploded. His message is to people his own age: here's how you can help a guy like me to heal on the inside too."

Helping Children Heal the Effects of Loss and Trauma after Burn Injury: A Guide for Parents and Caregivers - \$3.00

Author: Megan Bronson RN, MSN, CS
Available from the Phoenix Society,
<http://www.phoenix-society.org>.

"This 23-page booklet offers tools to define, identify, and support grief, loss and trauma in children affected by burns. You will also find an extensive list of resources to aid in supporting children and youth at your home or clinical setting. Burn injury, treatment, and recovery require ongoing care and support for children who have been affected by burn trauma and the losses associated with that. Providing tools to educate burn professionals and families on the appropriate ways to help children cope with the grief, loss, and trauma of burn injury will help create environments, both at home and in-patient and out-patient treatment settings, for emotional healing to take place."

I Can Make It One More Day - \$7.95

Author: David Snitker
Publisher: Breline Publishing Co.
Available from the Phoenix Society,
<http://www.phoenix-society.org>.

In the burns ward

Author: Read, Elizabeth J.
Publication: Melbourne: Royal Children's Hospital, 1979

It's Not What Happens to You, It's What You Can Do About It - \$19.95

Author: W. Mitchell
Publisher: Phoenix Press
Available from the Phoenix Society,
<http://www.phoenix-society.org>.

Journeys Through Hell - \$27.95

Author: Dennis J. Stouffer, Ph.D.
Publisher: Rowman & Littlefield, 1994
Available from the Phoenix Society,
<http://www.phoenix-society.org>.

The author is a member of the Board of Directors of the Alisa Ann Ruch California Burn Foundation and an Emergency Planning and Management Specialist for Hughes Aircraft Company. He has a Ph.D. in Sociology (University of California, Union Institute) and has done extensive research on the long-term consequences of burn injury.

"Journeys Through Hell is an important book that takes the reader into the inner, private lives of burn injury survivors.

This is a gem of a book, a social psychological study that relies on the narrative stories provided by burn survivors themselves who, in biographical fashion let us look at what it means to be a survivor of a terrible injury. What it means, very much unanticipated by the severely injured person in the initial stages of the injury, is pain, anguish, torture, and very importantly, hope and anticipation of a healed future.

While the book focuses on severe burns, it really has a much broader appeal: it is really about what it means to be a trauma survivor. The trauma could be physical, psychological or both. In any case, the book is about how people experience the most extreme personal loss, and sudden, terrifying change. In instantly experiencing the destruction of their normal, everyday lives, and in having their worlds shattered, we see how the survivors slowly struggle to be reborn, and come whole again."

Legal Rights of the Catastrophically Ill and Injured: A Family Guide - Free

Author: Joseph L. Romano, Esquire
Available from the Phoenix Society,
<http://www.phoenix-society.org>

Little Tree: A Story for Children With Serious Medical Problems. - \$8.95

Author: Mills, Joyce C.
Publisher: Magination, 1992.

Originally written for a young girl about to undergo amputation, the book will touch any child who suffers from a serious illness, accident, burns, or death.

Manual of burn therapeutics: an interdisciplinary approach

Author: Salisbury, Roger E; Newman, Nancy Marville.

Publisher: Boston: Little, Brown, 1983

Michael's story: the story of a burn victim

Author: Brunette, Joan.
Publisher: Kettering, OH: PPI, 1995

My Stupid Illness - \$14.95

Author: Tartakoff, Katy
Publisher: Children's Legacy, 1994

Provides children and families with life-threatening illnesses such as cancer

and AIDS, burns, cystic fibrosis and many others, an opportunity to document their lives in a book form. The book is also helpful with people experiencing a recent loss, abuse, neglect, abandonment or fear about something in everyday life. It invites creative expression through the use of photography, drawing, writing, and collage making. It is a life-journal that encourages open communication.

Rising from the Flames: The Experience of the Severely Burned - \$24.95

Author: Carter, Albert Howard, Jane A. Petro, and Albert Howard III Carter.

Publisher: University of Pennsylvania Press.

"Examines the experience of the severely burned as survivors confront it, not just as a medical event but as a human ordeal involving social, cultural, psychological, and medical trauma. Discusses the causes of burns, the physiology of injury and healing, the forms of isolation patients endure, and the cultural meanings attached to burns and burned persons."

Severe Burns: A Family Guide to Medical and Emotional Recovery – \$24.95

Author: Andrew M. Munster, M.D.

Publisher: Johns Hopkins University Press, 1993

This is a great resource for information on Burns and Recovery.

From Library Journal:

"Munster, a professor of surgery and plastic surgery who has specialized in the care of burn patients for the past 25 years and who is director of the Baltimore Regional Burn Center, candidly discusses the medical and psychological care that burn patients receive. Written for lay readers, his guide presents a wide range of clearly explained medical information--types of burns, stages of treatment and recovery, pain management, physical rehabilitation, plastic surgery, and so forth. Munster is sensitive to the needs of young burn survivors, and he also includes a few inspirational stories by burn survivors. However, feelings about surviving and living a fulfilling life after a severe burn are not deeply explored,

leaving the reader longing for more emotional survival information. Informative appendixes include a list of burn care services and a glossary. Recommended for public libraries and consumer health collections."

Therapy for the burn patient

Author: Leveridge, Annette.

Publisher: London : New York: Chapman & Hall, 1991

Up from the Ashes: Surviving and Growing Through Personal Crisis - \$12.95

Authors: Karl Slaikeu and Steve Lawhead

Publisher: Zondervan Publishing Company

Available from the Phoenix Society,

<http://www.phoenix-society.org>.

Newsletters:

Burn Support News – The Phoenix Society newsletter, <http://www.phoenix-society.org>

"The quarterly news publication, *Burn Support News*, publishes articles about individuals who have made the successful transition from burn victim to burn survivor. It also offers information about services throughout the country and details about Society programs and resources. *Burn Support News* has a circulation of more than 10,000."

Article reprints can be found on the Phoenix Society website under family resources.

Seminars:

1999 Burn Survivor Wellness Forum

The Forum was a one-day seminar designed to inform and help burn survivors, their families, friends and other interested persons.

For availability and pricing call the offices of Romanucci & Blandin at 312-458-1000.

Videos:

Burn Survivors Video (web only) – 9 mins.

"A video presentation that profiles burn patients treated at the nationally acclaimed UW Medicine Burn Center at Harborview Medical Center. Each year the burn center sees more than 500 patients, one third of these are children.

With a survival rate of 96 percent, the burn center at Harborview is truly a remarkable place. State of the art technology and care by a multidisciplinary team make the burn center one of the best in the country."

Available at:

<http://www.uwmedicine.org/Facilities/Harborview/ClinicsAndServices/Burn/BurnSurvivorsVideo.htm>

Lane's Road Home – 12 mins. - free (s&h \$5.00)

"The video chronicles the recovery process of a young burn survivor, burned over 85% of her body, and includes aspects of recovery, integration back into her family at home, and perspectives from her family members. Portions are narrated by Megan Bronson, RN, MSN, CS to help children and families through each stage of recovery. The points highlighted in the video correspond to 'Helping Children Heal the Effects of Loss and Trauma After Burn Injury; A Guide for Parents and Caregivers.'"

Available from the Phoenix Society,
<http://www.phoenix-society.org>

Reservoirs of Strength – 57 mins. - \$60.00

"A close and careful look at burn rehabilitation through the eyes of the patients, their friends and loved ones, and the many specialists who contribute to the miracle of recovery."

Available from the Phoenix Society,
<http://www.phoenix-society.org>

You Can Do It!– 20 mins. - \$60.00

"Community Reentry Skills for Children, Teens and Adults with Burns"

Available from the Phoenix Society,
<http://www.phoenix-society.org>

Websites:

American Burn Association
<http://www.ameriburn.org>

Dedicated to the study and research in acute care, rehabilitation and prevention of burns.

"The American Burn Association and its members dedicate their efforts and resources to promoting and supporting burn-related research, education, care, rehabilitation, and prevention."

Burn Support Groups Database

<http://www.burnsupportgroupsdatabase.com>

A database of burn support groups arranged by state including burn camps for children. Website is available in nine languages.

Burn Survivors Online

<http://www.burnsurvivorsonline.com/>

As a service of the World Burn Foundation, BSO provides support for burn victims and their families. Includes survivor profiles, a chat room, links to assistance, articles, inspirational stories, types of burn injuries and scars, scar revision, guides, and more. "Through its direct support services and affiliations with other burn related support and awareness programs, WBF aims to assist those who have suffered a severe burn trauma, and to help individuals access the services and support they need to aid in their recovery."

Burn Survivor Resource Center

<http://www.burnsurvivor.com/index.html>

This site contains medical information as well as information on support groups, resources, and legal services for burn survivors. "This site is being offered as the premier one stop resource center to ensure professional information is made available to the burn survivor, to the many people who are searching for critical information on behalf of a loved one, to the family and to the professionals. We hope that this site will be able to assist you with valuable advice, guidance, products and support that otherwise might not be easily available to you."

Burn Survivors throughout the World

<http://www.burnsurvivorsttw.org/storieslist.html>

A list of stories from burn survivors throughout the world.

The Hurting Angels: Survivors supporting Survivors

<http://www.thehurtingangels.com>.

This site is oriented towards children and their parents, and features a free downloadable coloring book for burned children.

The National Burn Victim Foundation

<http://www.nbvf.com/pages/859631/index.htm>

"The National Burn Victim Foundation is a non-profit service agency founded in 1974 to address the problems associated with burn injuries and their prevention through consultation and education. The NBVF also serves as an advocate for burn survivors and their families. The Foundation has provided free emergency services to more than 3,000 New Jersey burn survivors since 1976."

The Peoples' Burn Foundation

<http://www.peoplesburnfoundation.org/Welcome.htm>

Created by a burn survivor, this organization's website contains links to support groups, "Ask an Aesthetician" for skin care information, and a short story called "Stare with Care" that provides insight into the feelings of a burn survivor, among other things.

The Phoenix Society for Burn Survivors

<http://www.phoenix-society.org>.

"The Phoenix Society is a non-profit organization whose mission is to provide support to anyone affected by a burn injury through peer support, education, collaboration, and advocacy. Our programs and services provide burn survivors and those who care for them, a network of resources and opportunities for a happier, healthier, and more hopeful life. The Phoenix Society's goal is to assure that all burn survivors have access to the support systems necessary for their recovery. The Society encourages and supports activities that bring survivors together to

learn and grow from their common experiences. It provides emotional support and shares coping strategies with those affected by burn injuries and those who care for them. The Phoenix Society acts as an advocate for quality burn care and burn prevention at the National level. Most of the services offered by The Phoenix Society are focused on peer support and provide information and access to resources."

Shriners Burn Survivor Study

http://www.shrinershq.org/whatsnewarch/archive_s00/jama1-00.html

"An extensive, long-term study by researchers at the Shriners Hospital in Boston, published in the *Journal of the American Medical Association*, shows that most children who survive massive burns, i.e. burns involving more than 70 percent of their bodies, can expect to have a quality of life comparable to children their ages in the general population."

Shriners Patient Success Stories

<http://www.shrinershq.org/patients/cj7-00.html>
<http://www.shrinershq.org/patients/zeigler9-99.html>

Farewell, Vicki

In the last edition of *Into the Stacks*, we welcomed, Pitt student, Vicki Goode for a 15 week internship. In this issue, we bid Vicki adieu, and wish her all the best as she completes her Master of Library and Information Sciences degree this summer. Vicki completed her field placement with our Library this month. Highlights of her accomplishments include:

- providing collection development input toward the Patient and Family Education Center print collection
- developing a color-coded system of cataloging print materials in the PFEC
- processing interlibrary loan requests using DOCLINE
- performing literature search requests using OVID database suite and PubMed
- becoming familiar with MarciveWeb SELECT in the acquisition of MARC

records, book label sets and catalog cards

- becoming familiar with maintenance of a hospital library website
- becoming familiar with the daily operations of managing a hospital medical library and patient and family centered information center

Thanks to Vicki for all of her efforts and dedication! Her assistance was invaluable.

Appreciation for your support to the Library Fund

The Hospital and the Richard M. Johnston Health Sciences Library would like to thank the following donors to the Library Fund who help make acquisitions possible:

- Dr. and Mrs. C. Lee Walter
- Mary Jo Dorsey

If you are interested in making a donation to the Library, please contact Mary Jo Dorsey at 412-578-4708 or email at mjdorsey@wpahs.org or Beverly Beisgen at the WPH Foundation at 412-578-4049.

Library Committee

The most recent meeting of the Library Committee was held on March 15, 2004.

Topic covered included a presentation of new resources available from library homepage including:

- Oncology Panel, oncology resources on the Web
- Evidence Based Medicine Resources
- Library Fact Sheets
- Community of Science
- Images.MD trial (through March)
- Physician Portal

The Committee also discussed strategies for replacing the 18 public use computers in the Library.

If you are interested in becoming a member of the Library Committee, please contact Mary Jo Dorsey at 412-578-4708 or mjdorsey@wpahs.org.

Library Education and Outreach

If your department would like to schedule a Library Orientation presentation at a noon conference or any other time, please contact

Mary Jo at 412-578-4708 or email at mjdorsey@wpahs.org.

Recent classes include: *HTML basics* and *What you didn't know about PubMed*