

## STARBRIGHT EXPLORER SERIES

Starbright Foundation, 2001

This CD-ROM includes a spotlight on IV's, the Sickle Cell Slime-O-Rama Game, Secrets of Spinal Fluid, Bone Marrow Aspiration & Biopsy, Radiology Center, Exploring Our Incredible Blood, Fitting CF into Life, Living with Kidney Disease (recommended ages 6-15)

## LIVING WITH KIDNEY DISEASE

This CD-ROM was designed for preteens/teens to offer insight into diet, body image issues, kidney physiology and treatment options. It also offers advice on how to talk to friends about it, fit in treatment and maintain a positive outlook.

## SICKLE CELL SLIME-O-RAMA GAME (CD-ROM)

An interactive quiz show that challenges players to answer questions about sickle cell disease. It focuses on pain management, daily life situations and the importance of communicating pain.

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Books are available through the lending library on many specific chronic illnesses. Books and topical bibliographies are available on the following topics:

Arthritis	HIV/AIDS
Allergy/Asthma	Cancer
Cardiac	Cranial Facial
Cystic Fibrosis	Diabetes
Epilepsy	Fibromyalgia
Hemophilia	Hospitalization
Limb Deficiency	Muscular Dystrophy
Pain Control	PKU
Scoliosis	

Last updated 7/2009

*NH Family Voices Lending Library*

# Books on Chronic Health Conditions



NH Family Voices  
Toll free in state 1-800-852-3345 X 4525  
or (603) 271-4525  
nhfv@yahoo.com  
www.nhfv.org

New Hampshire Family Voices has available the following materials in the lending library.

Children's books are marked with a ♥.

Books can be requested by phone or via the website and are sent through the mail with a postage paid return envelope.

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♥ ***LET ME SHOW YOU MY WORLD***

The Children's Legacy, 1994

An activity book that provides children and families with life-threatening illnesses such as cancer, AIDS, CF an opportunity to document their lives in book form through creative expression using photographs, writings & drawings.

♥ ***MY STUPID ILLNESS***

The Children's Legacy, 1994

This activity book is much like the book "Let Me Show You My World". It provides children and families a way to document what is happening in their lives.

♥ Mills, Joyce C.

***LITTLE TREE: A STORY FOR CHILDREN WITH SERIOUS MEDICAL PROBLEMS***

Magination Press, 1992

Although she is saddened that storm damage has caused her to lose some of her branches, Little Tree draws strength and happiness from the knowledge that she still has a strong trunk, deep roots and a beautiful heart.

♥ Miles, Brenda S., PhD

***IMAGINE A RAINBOW: A CHILD'S GUIDE TO SOOTHING PAIN***

Magination Press, 2006

A colorful story and a great tool for introducing children to use their imagination to deal with pain & anxiety. Includes a section for parents on using imagery & breathing exercises.

***COPING & CONNECTING: TEENS TALK ABOUT LIVING WITH A CHRONIC ILLNESS***

Children's Healthcare, 1997

A very encouraging video, in which teens speak about what it is like to be diagnosed with a chronic or life-threatening illness, and what helps them to cope. Cancer, asthma, and diabetes are among the illnesses addressed. (about 60 mins)

***VOICES OF EXPERIENCE: KIDNEY AND LIVER TRANSPLANT PATIENTS SHARE THEIR SUCCESS STORIES***

Fujisawa Healthcare, 2001

This video and accompanying journal were designed to educate patients about transplant process, useful tips on preparing for and living with a transplant. Transplant patients share their experiences.

***PARENTING THE INFANT WITH PROLONGED HOSPITALIZATION***

Child Development Media, Inc., 1996

Parents are encouraged to become involved with their infant to the extent possible. This video covers things parents can do to help themselves cope during this difficult time of having a child hospitalized. (12 minutes)

***PLASTIC EGGS OR SOMETHING!? CRACKING HOSPITAL LIFE***

Starbright Foundation, 1998

An inside look at hospital life, including check in, getting treatment, sharing a room & eating the food. (For teens.)

***WHAT AM I, CHOPPED LIVER? COMMUNICATING WITH YOUR DOCTOR***

Starbright Foundation, 1998

Teens express the ways they have been able to communicate with their doctors.

Therriault, V.M., RN, MSN, ARNP

***GASTROESOPHAGEAL REFLUX DISEASE***

McGowan Consultants, 1995

This manual addresses all aspects of gastro esophageal reflux disease and many of the issues faced by someone suffering with it.

***A PARENTS GUIDE TO TRACHEOSTOMY HOME CARE FOR YOUR CHILD***

Mallinckrodt Medical, Inc., 1996

Provides tips on how to suction, change ties, change tubes and care for the skin around the opening. Gives suggestions for daily living, safety and solving problems.

Maddrey, Willis C. MD & Schiff, Eugene R. MD

***BE IN CHARGE - A GUIDE TO LIVING WITH CHRONIC HEPATITIS B AND C***

Covers all aspects, disease, daily living as well as future planning.

## VIDEOS (VHS)

***BACK TO SCHOOL: TEENS PREPARE FOR SCHOOL RE-ENTRY***

Starbright Foundation, 2000

Teens who have been to school following illness or injury share stories and advice. Tips include getting involved, staying positive, talking to friends and standing up for their rights. School re-entry resources included. (25:31 mins.)



♥ Huegel, Kelly

***YOUNG PEOPLE AND CHRONIC ILLNESS - TRUE STORIES, HELP AND HOPE***

Free Spirit Publishers, 1998

Offers advice, suggestions and strategies to help readers develop a positive relationship with their doctors, talk to their friends, communicate with family members and fit in at school. Everything you need to know to manage the illness on your own terms.

♥ Kaufman, Miriam, MD

***EASY FOR YOU TO SAY: Q & A'S FOR TEENS LIVING WITH CHRONIC ILLNESS OR DISABILITY (REVISED)***

Firefly Books, 2005

Written in a clear, upfront manner, this book answers questions commonly asked by teens with chronic illness or disability on topics ranging from family relationships to dating, sexuality, and medical care.

♥ Sileo, Frank J., PhD

***TOILET PAPER FLOWERS: A STORY FOR CHILDREN ABOUT CROHN'S DISEASE***

Health Press, 2005

Julia is very excited to be having her friend Nikki stay over. During the sleepover, Julia explains Crohn's disease to her new friend. A wonderful story for children with Crohn's disease, their siblings and classmates.

♥ Wood, Ramona

***NOW CAITLIN CAN: A DONATED ORGAN HELPS A CHILD GET WELL***

ABC Press, 2004

Written by a family, this tells the story of Freddie's little sister, Caitlin, from birth to the point of her kidney transplant. After the transplant, she can eat and play just like Freddie does.

♥ Crowe, Karen

***THE INSIDE STORY: A KID'S GUIDE TO KIDNEY AND LIVER TRANSPLANT***

Fujisawa Healthcare, 2001

Written for children who will be having a transplant, this book addresses many of the common questions & concerns.

♥ ***MY PKU TOOLKIT: A TRANSITION GUIDE TO ADULT PKU MANAGEMENT***

Applied Nutrition Press, 2007

Written for teens, this guide provides basic information about PKU, and lots of tips on how to make the transition to adult healthcare, managing their own care.

♥ Low-Dumond, Sabrina

***WEAKLING WILLIE***

PublishAmerica, 2008

Willie is a rhinoceros beetle, and is supposed to be strong, but his muscles are very weak. See how Willie learns to appreciate his other strengths. The author's son has Pompe disease, a metabolic disorder.

Detzer, Mark J. PhD

***VOICES OF HOPE: TEENAGERS AND YOUNG ADULTS WITH COLITIS AND CROHN'S DISEASE***

Dartmouth Medical School at Dartmouth College, 1999

Addresses many of the issues that face young people with colitis and Crohn's disease. Many personal stories & tips.

Hoekstra, Elizabeth & Bradford, Mary

***CHRONIC KIDS CONSTANT HOPE: HELP AND ENCOURAGEMENT FOR PARENTS OF CHILDREN WITH CHRONIC CONDITIONS***

Crossway Books, 2000

Written by two parents of children with chronic health conditions. This is a very faith based book which offers tips on dealing with emotions, responding to insensitive remarks, navigating insurance and medical care issues.

***PATIENT AND FAMILY HANDBOOK: FOR THE PRIMARY IMMUNE DEFICIENCY DISEASE***

Immune Deficiency Foundation, 2001

This book was written to help patients and their families learn more about the immune system, the primary immune deficiency diseases and currently available therapies and some possible treatments.

Platt, Allan F., P.A.-C. ; Sacerdote, Alan, MD

***HOPE AND DESTINY: THE PATIENT AND PARENT'S GUIDE TO SICKLE CELL DISEASE AND SICKLE CELL TRAIT (REVISED)***

Hilton Publishing, 2006

In addition to providing the ABC's of sickle cell disease in a very easy to read format, this book contains a wealth of information on living a full and rich life while managing this condition.

Dwyer, John

***THE BODY AT WAR: THE STORY OF OUR IMMUNE SYSTEM***

Allen & Unwin, 1988, 1993

This book describes the immune system and how it works.

Mullen, Barbara Dorr & McGinn, Kerry Anne RN, BSN, OCN

***THE OSTOMY BOOK: LIVING COMFORTABLY WITH COLOSTOMIES, ILEOSTOMIES & UROSTOMIES***

Bull Publishing Company, 1980, 1992

A complete reference book and a moving, often funny and heartwarming account of the experience of having an ostomy and the good life that can follow. Helps with practical information, boosts moral and provides an honest look at stoma surgery.

Dahlberg, Axel and Love, Janis Russell

***FOREVER HELLOS, HARD GOODBYES: INSPIRATION, WIT & WISDOM FROM COURAGEOUS KIDS FACING LIFE-THREATENING ILLNESS***

Free Spirit Publishing, 2008

In their own words, 32 children & young adults share what it is like to live with a life threatening illness. They openly talk about the good stuff, the bad stuff, their hopes, boredom, tears, and laughter, as well as their desire to be treated like anyone else.

Wallace, H.; Biehl, E.; MacQueen, J. & Blackman, J.

***MOSBY'S RESOURCE GUIDE TO CHILDREN WITH DISABILITIES AND CHRONIC ILLNESS***

Mosby-Year Book, Inc., 1997

This comprehensive book covers the history and the future of issues and the solutions to providing healthcare to children with special health care needs.

Larson, Georgianna RN, PNP, MPH & Kahn, Judith A. MSW  
***HOW TO GET QUALITY CARE FOR A CHILD WITH SPECIAL HEALTH NEEDS***

Lifeline Press, 1990

A consumer's guide to getting quality care for the child with special health care needs. Carefully researched and easy to use, this book shows you how to plan for your child's health needs.

Leff, Patricia Taner and Walizer, Elaine H.

***BUILDING THE HEALING PARTNERSHIP***

Brookline Books, 1992, 1994

An empathetic and practical guidebook relevant to the families of chronically and severely ill children and to those who care for them. Observes and evaluates from the inside, with intimacy, understanding and compassion. Weaves together brief vignettes to teach.

Eveloff, Scott E., MD

***BOTH SIDES OF THE WHITE COAT: AN INSIDER'S PERSPECTIVES ON THE CRITICALLY ILL CHILD***

People with Disabilities Press, 2000

Personal account of the first seven years of life with a child with congenital muscular dystrophy, as told by a father who is also a physician.

Power, Paul W., SC.D. & Orto, Arthur Dell, PhD.

***THE RESILIENT FAMILY: LIVING WITH YOUR CHILD'S ILLNESS OR DISABILITY***

Sorin Books, 2003

Written for parents of children with a serious illness or disability, this book will help families to identify their strengths, recognize the needs of all family members, learn to manage stress, and deal with medical providers.

Fuller, Dawn Winkelman

***THE HEART OF JOSHUA: A STORY OF HOPE FOR ALL PARENTS OF CHILDREN WITH CHRONIC ILLNESS***

University of Toronto Press, 1987

Addresses the roller coaster of emotions, care and experiences of having a child with a chronic illness.

Moynihan, Patricia RN, PNP, MPH & Haig, Broatch, RD, CDE  
***WHOLE PARENT WHOLE CHILD: A PARENT'S GUIDE TO RAISING A CHILD WITH CHRONIC ILLNESS***

DCI Publishing Co., 1989

Covers age ranges such as birth to age 1, toddler, pre-school etc.. Parenting issues, development, emotional needs of child, working with schools and everyday concerns.

Trachter, Amy, Psy.D., Ph.D.

***COPING WITH CROHN'S DISEASE***

New Harbinger Publications, 2001

Management of the physical and emotional challenges of Crohn's Disease, including making the decision to tell people.

Krane, Elliot J., MD

***RELIEVE YOUR CHILD'S CHRONIC PAIN***

Fireside Books, Simon & Schuster, 2005

Approximately 10 million children live with chronic pain. This book provides tips on recognizing and rating pain and learning alternative pain management strategies. It also dispels fear about addiction to pain medication, and provides information about pain clinics.

Arnold, Martha J. & Silkworth, Cynthia K., editors

***THE SCHOOL NURSE'S SOURCE BOOK OF INDIVIDUALIZED HEALTHCARE PLANS***

Sunrise River Press, 1993

A compilation of plans covering the most frequently encountered chronic and acute health issues. (e.g. asthma, arthritis, cancer, cystic fibrosis, diabetes, epilepsy)

\* We also have volume II, published in 1999, which covers, among others, *Fragile X, Burns, severe allergies, Mitochondrial disorders, Prader-Willi, Spinal Cord Injury*

Pitzele, Sefra Kobrin

***WE ARE NOT ALONE: LEARNING TO LIVE WITH A CHRONIC ILLNESS***

Thompson & Company, Inc., 1985, 1986

Guidelines around the psychological aspects of chronic illness and family relationships.

Levert, Suzanne

***WHEN YOUR CHILD HAS A CHRONIC ILLNESS: WHAT YOU MUST KNOW, WHAT YOU CAN DO, WHAT YOU SHOULD EXPECT...***

Lynn Sonberg Book, 1995

Provides parents with information and practical ideas for solving everyday problems they will face in dealing with medical and health care systems.

Jones, Monica Loose

***HOME CARE FOR THE CHRONICALLY ILL OR DISABLED CHILD: A MANUAL & SOURCE BOOK FOR PARENTS AND PROFESSIONALS***

Harper & Row Publishing Co., 1985

A bit old, but still informative this book teaches parents about the daily care of an ill or child with a disability, enabling them to respond to emergencies, teaching how to effectively carry out many medical procedures.



Borfitz, Jeanne M.

***THE HOME-CARE BOOK: A PARENT'S GUIDE TO CARING FOR CHILDREN WITH PROGRESSIVE NEUROLOGICAL DISEASES***

National Tay-Sachs/Allied Diseases

This care manual is intended to offer practical assistance for those who have chosen to care for their children at home. It is written for parents who are ready to deal with explicit information and are seeking answers.

Finn, Robert

***ORGAN TRANSPLANTS: MAKING THE MOST OF YOUR GIFT OF LIFE***

O'Reilly, 2000

Provides information on making the transplant decision, choosing a transplant team, how a match is determined, the transplant itself, anti-rejection drugs, emotional responses, finding support. Includes stories of transplant recipients.

Lewis, Kathleen

***SUCCESSFUL LIVING WITH CHRONIC ILLNESS: CELEBRATING THE JOYS OF LIFE***

Lupus Foundation of America, Inc., 1994

This book presents a unique, insightful perspective into the difficulties of chronic illness.