

## **Books about Cystic Fibrosis for Parents**

- An Introduction to Cystic Fibrosis For Patients and Families by James C. Cunningham, MD et.al., 2003 (Include DVD)
- A Way of Life: Cystic Fibrosis Nutrition Handbook and Cookbook by Lisa Davis, MS, et.al., 2008
- Beginning CF Care, A guide for parents of young children by Baylor College of Medicine, 2010
- Breathing for a Living: A Memoir by Laura Rothenberg, 2003
- Cystic Fibrosis – A Guide for Patient and Family by David M. Orenstein, 2004 New 3<sup>rd</sup> Ed. (published 2011) is on order
- Cystic Fibrosis – Medical Care by David M. Orenstein, MD et.al., 2000
- Fat and Loving It! By Gail Farmer, et.al., 1990
- Guide to Health Insurance Coverage for People living with Cystic Fibrosis, Beth Sufian, 2008
- Managing Cystic Fibrosis Related Diabetes, An Instruction Guide for Patients and Families by Dana Hardin, et.al., 2008
- Our Child Has Cystic Fibrosis: What do we do about school by Carla Woyak, 2004
- Psychosocial Aspects of Cystic Fibrosis by Myra Langer-Bluebond, et.al., 2001
- Run, Amy, Run! By Beth Huffman, 2010
- Sick Girl Speaks! : Lessons and Pondering Along the Road to Acceptance by Tiffany Christensen, 2007
- The Lung Transplantation Handbook by Karen Couture, 2001
- The Power of Two: A Twin Triumph over Cystic Fibrosis by Isabel Stenzel Byrnes, et.al., 2007

## **Books about Cystic Fibrosis for Teens**

- Cystic Fibrosis by Ruth Bjorklund, 2009
- Cystic Fibrosis (Diseases and Disorders) by Melissa Abramovitz, 2003
- Cystic Fibrosis: The Ultimate Teen Guide by Melanie Ann, 2006
- Explaining Cystic Fibrosis by Jillian Powell, 2009
- Stevie's Secret by Shader Diane Smith, 1999

## **Books about Cystic Fibrosis for Children**

- CF and Me – Helps child to begin to understand about CF by Susan Tumiel Smith, M. Ed., 1995
- Little Brave Ones by Carrie Lux, 2005
- Taking Cystic Fibrosis to School by Cynthia Henry, 2000

## DVD's about Cystic Fibrosis

- Becoming Christopher - A portrait of a young man living with CF stepping into adulthood, Novartis, 2008
- Christopher Chronicles - A Young Man with CF navigates self-management while juggling a career and social life, Novartis, 2008
- Coughing the Distance with Cystic Fibrosis by Lucas Li, 2009
- Expanding the Horizon of Hope by Cystic Fibrosis Foundation, 2005
- In the Mix – Dealing with Death- Teens talk about dealing with the death of someone close, Castleworks, 2000
- Medicare and Social Security, PCH CF Center Presentation featuring Ann Marie Grande and Maxine Baker, 2009
- Raising Meghan - the story of a family's struggle to let go and prepare their teenage daughter with CF for independence and self-care, Novartis, 2009

## Websites about Cystic Fibrosis

### Cystic Fibrosis Foundation – <http://www.cff.org/>

United States Cystic Fibrosis Organization for major research, education, patient advocacy and fundraising. Has a wide range of educational materials available for download and also in video format. Also links to the Cystic Fibrosis Services Pharmacy, where patients can obtain their needed

### Cystic Fibrosis.com – <http://www.cysticfibrosis.com/>

Patient support website with multiple support group connections in the form of forums, blogs, newsletters. Also links to many videos both educational and informational. Also info on clinical research studies. Some portions of the site require registration.

### Boomer Esiason Foundation – <http://www.esiason.org/>

Information, videos, events.

### Cystic-L – <http://www.cystic-l.org/index.htm>

It's an Email Community! It's a Website!

### The Heroes of Hope program – <http://www.heroesofhope.com/heroesofhope/>

Recognizes and salutes unique individuals with cystic fibrosis who strive to live full, productive lives and serve as role models to others, while managing their own healthcare needs.

### CF Infants and Toddlers – [http://health.groups.yahoo.com/group/CF\\_Infants\\_Toddlers/](http://health.groups.yahoo.com/group/CF_Infants_Toddlers/)

Yahoo Group (online message board) for Parents of young patients with Cystic Fibrosis. Must "join" (free) to participate.

### Cystic Fibrosis in the Classroom – <http://www.cfri.org/pdf/2008CFintheClassroomEnglish.pdf> Print the Booklet

**For a comprehensive list (15 pages!) of Websites about many aspects of Cystic Fibrosis – go to <http://www.cfri.org/pdf/weblinkguide.pdf>**

## **Books about Parenting a Child with Chronic Illness**

- Armful of Time, The Psychological Experience of the Child with a Life-Threatening Illness by Barbara Sourkes, Ph.D., 1995
- Coping with Your Child's Chronic Illness by Alesia Barrett Singer, M.A., 1999
- In Sickness and in Play, Children coping with chronic Illness by Cindy Dell Clark, 2003
- Married with Special-Needs Children by Laura E. Marshak, Ph.D., et.al, 2007
- Parenting Children with Health Issues by Foster W. Cline, M.D. et.al., 2007
- Shelter From the Storm, Caring for a Child with Life Threatening Condition by Daniel R. Tobin, M.D. et.al., 2003
- Special Needs Trusts, Protect you child's financial future by Attorney Stephen Elias, 2009
- The Resilient Family, Living with Your Child's Illness or Disability by Paul W. Power, ScD. et.al., 2003
- The Special Needs Planning Guide, How to prepare for every stage of your child's life by John W. Nadworny, et.al., 2007

## **Books about Living with a Chronic Illness**

- Coping with Chronic Illness by Barbara Moe, 1992
- Easy For You To Say, Q&As For Teens Living with Chronic Illness or Disability by Miriam Kaufman, MD, 2005
- Forever Hellos, Hard Goodbyes, Inspiration, Wit & Wisdom from courageous kids facing life threatening illnesses by Axel Dahlverg, et.al., 2008
- Living a Healthy Life with Chronic Conditions by Kate Lorig, RN, et.al, 2006
- Primary Care of the Child with a Chronic Condition by Patricia Jackson, RN, MS, et.al, 2009
- Young People and Chronic Illness, True Stories, Help, and Hope by Kelly Huegel, 1998

## **Websites for Parenting a Child with a Chronic Illness**

**Parenting Children with Health Issues Website** - Free living with CF pamphlets

<http://www.parentingchildrenwithhealthissues.com/catalog/item/7761577/8280353.htm>

For raising responsible kids with a chronic illness - **Free** online videos

<http://www.parentingchildrenwithhealthissues.com/FreeVideoClips.html>

**Raising Special Kids** – <http://www.raisingpecialkids.org/> Local support organization

**Workshop for the Siblings of Children with Chronic illness - Ryan House Sibshops Collaborative** –

Primary Contact: Holly Cottor at 602-200-0767

Please visit [www.ryanhouse.org](http://www.ryanhouse.org) website for additional information on upcoming Sibshops!

**The Center for Children with Special Needs** – <http://cshcn.org/planning-record-keeping>

Printable forms to use in creating a Care Notebook for your child/children.

## Relaxation Books and CD's

### Adults:

- Deep Stress Relief: Total Relaxation & Guided Relaxation by Kelly Howell, 2006 (Audio CD)
- Healing Images for children, Teaching Relaxation and Guided Imagery to Children by Nancy Klein, M.A., 2001
- Health Journeys: Meditations to Relieve Stress by Belleruth Naparstek, 1995 (Audio CD)
- Kitchen Table Wisdom, Stories That Heal by Rachel Naomi Remen, M.D., 1996
- Ready, Set, R.E.L.A.X by Jeffrey Allen, M.Ed., et.al., 1996
- Relax Rx: a Self-Hypnosis Program for Health and Well-Being by Steven Gurgevich, 2008 (Audio CD)
- The Extraordinary Healing Power of Ordinary things by Larry Dossey, M.D., 2006
- Visionary Path by Various Artists, 1997 (Audio CD)

### Teen:

- Fighting Invisible Tigers, Stress Management for Teens by Earl Hipp, 2008

### Children:

- A Boy and A Bear, the children's Relaxation Book by Lori Lite, 1996
- Moon Beam, A book of meditations for children by Maureen Garth, 1992
- Rainbows and Sunshine (Age 6-11) by Airy Melody Music, 2008 (Audio CD)
- The Star Within by Roxanne Daleo, 2001 (Audio CD)
- The Swan and the Mermaid (Age 3-6) by Airy Melody Music, 2008 (Audio CD)
- Waves and Light (Age 11 and up) by Airy Melody Music, 2008 (Audio CD)

## Other helpful websites

### Relaxation Techniques for Stress Relief –

[http://www.helpguide.org/mental/stress\\_relief\\_meditation\\_yoga\\_relaxation.htm](http://www.helpguide.org/mental/stress_relief_meditation_yoga_relaxation.htm)

Online audios and videos for Relaxation – <http://www.oneonta.edu/development/counseling/pages/relaxation.asp>

Starbright World - [http://www.starbrightworld.org/default\\_login.aspx?ReturnURL=%2fhome.aspx](http://www.starbrightworld.org/default_login.aspx?ReturnURL=%2fhome.aspx)

An online social network where teens (ages 13 to 20) who have serious medical conditions, and siblings of seriously ill teens, can connect with each other via moderated chat rooms, games, bulletin boards, videos, and more.