



## LFA SEAL OF APPROVAL MATERIALS

Revised August 11, 2008

*Items with code # are available though LFA's online store at [shop.lupus.org](http://shop.lupus.org)*

### AUDIOCASSETTES

#### **Empowerment Series: Diagnosis: Lupus, The Journey and the Challenge**

by Leslie Kane and Roderick A. Borrie, Ph.D. 1997. Call Patient Communications (516) 689-1223 or write to: Patient Communications, P.O. Box 2876, East Setauket NY 11753.

#### **Guided Meditation to Help You With Rheumatoid Arthritis or Lupus** (approved 2002)

by Belleruth Naparstek. Health Journeys, Time Warner. This information is esigned to help the body reduce inflammation, soreness, excess fluid; to help replace eroded bone and joint tissue; to help overactive, misguided immune cells subside; to encourage more softness toward the self; to reduce pain; and to encourage feelings of relaxation, safety, love and peace. Side B has affirmations. (Running time: 50 minutes). \$12.98.

#### **Hypnocise! Eastern and Western Exercise Techniques (Level One)** audiotape and booklet (approved 2005)

by Nicolette Schwartzman, Dipl.Ac. and Michael Legge, C.Ht. (Geo Sound Recording Studio, 1996) \$12.95, 30 minutes. "Begin by allowing your body to be completely relaxed..." This audiotape and the accompanying booklet explain progressive relaxation, deep breathing, and visualization, and the exercises use both Eastern and Western techniques to help build strength gradually while allowing the body to let go of tension caused by stress. Available by mail or phone order from Hypnocise, 84 Wheatsheaf Lane, Suite 125, Princeton, NJ 08540 or toll-free (888) 321-TAPE (321-8273).

#### **Mastering Relaxation Series: "Pain Management" and "Relaxation/Stress Management"**

by Roderick A. Borrie, Ph.D. 1992. Call Patient Communications (516) 689-1223 or write to: Patient Communications, P.O. Box 2876, East Setauket, NY 11753.

### BOOKS

**A Delicate Balance—Living Successfully with a Chronic Illness** (approved 1998)  
by Susan Milstray Wells (Perseus Publishing, 2000) ISBN 0-73-820323-8. Hardcover,  
312 pp, \$17.50.

**All About Fibromyalgia: A Guide for Patients and Their Families** (formerly *Making Sense of Fibromyalgia*, approved 1999) by Daniel J. Wallace and Janice Brock Wallace (Oxford University Press, 2002) ISBN 0195147537. In their earlier book, medical writer Janice Wallace and Dr. Daniel Wallace, a leading expert on this disorder, provided a comprehensive guide for both patients and professionals to this little known and poorly understood syndrome. In this book the Wallaces provide a thoroughly revised and updated version of that highly successful volume, incorporating a wealth of new information. This edition provides the current understanding of the disease as well as the latest drug treatments all laid out in clear and accessible language. Drawing on actual cases to illustrate their points, the authors help break through the isolation that people often feel when doctors misdiagnose or simply ignore their symptoms. This book addresses the crucial need for information on this disease while offering reassurance to patients and their families. Hardcover, 272 pp, \$30.00.

**Are You Really Listening? Keys to Successful Communication** (approved 2006)  
by Paul J. Donoghue, Ph.D. and Mary E. Siegel, Ph.D., authors of *Sick and Tired of Feeling Sick and Tired* (Sorin Books from Ave Maria Press, Inc., 2005) With a foreword by Joan Lunden (former co-host of ABC's "Good Morning America"), this guide to good listening addresses an issue that lies at the heart of successful intimate and work-based relationships. The book offers practical and specific approaches to listening difficulties and blocks that should be universally appealing to men and women, spouses and parents, employees and employers. One reviewer writes, "*Are You Really Listening?* can improve the quality of readers' relationships, both personal and professional. A delight to read." Paperback, 224 pp., \$14.95.

**Are You Tired Again...? I Understand**  
by Marilyn Deutsch, Ph.D. (Western Psychological Services, 1998) This activities workbook will help children understand how to live with a person who has a chronic illness or disability. Paperback, 42 pp. \$9.95 or package of five for \$45.00. Item # 136832

**The Art of Getting Well** (approved 2002)  
by David Spero, R.N. (Hunter House Inc. Publishers, Alameda, CA, 2002). Subtitled "A Five-Step Plan For Maximizing Health When You Have a Chronic Illness," this book is about positive steps to take toward achieving mental and physical wellness. The author is a nurse, journalist, and health educator who has lived with multiple sclerosis for 25 years. Paperback, 256 pp, \$15.95.

**Butterfly Traveller** (approved 2000)

Published by European Lupus Erythematosus Federation and Novartis Pharma. ISBN 3-933185-34-3. This small book is color-Item #d to provide medical phrases and questions in 12 languages. Paperback, 242 pages. \$15.95. Item #

**Celebrate Me! A Story to Foster Self-Esteem** (approved 2004)

Story and illustrations by Lynda Farrington Wilson. (NeoStrata Company, Inc., 2001). A fun, imaginative and useful book to aid both children and parents in gaining self-acceptance of the child's skin conditions. Emphasizing the variations in all the attributes of nature helps create a soothing context for viewing our own "differences." Booklet, 22 pp., free. Call (800) 225-9511 or write to book@neostrata.com.

**Challenges of Lupus: Insights and Hope** (approved 1999)

by Henrietta Aladjem (Avery Publishing Group, Garden City Park, NY, 1999) This book is now distributed by Penguin-Putnam Publishers. Call (800) 548-5757. ISBN 0-895298-81-3. Paperback, 238 pp. \$14.95.

**The Chronic Illness Workbook: Strategies and Solutions for Taking Back Your Life** (approved 2003)

by Patricia A. Fennell, MSW, CSW (New Harbinger Publications, Inc., Oakland, CA, 2001) A comprehensive long-term coping model that shows how you can integrate your chronic illness into a balanced and meaningful life. ISBN 1-57224-264-7. Paperback, 240 pp. \$16.95.

**Control Your Pain!**

by Robert Phillips, Ph.D. This easy-to-read booklet offers 144 concrete strategies for reducing and managing the pain of lupus. Balance Enterprises, Inc., 1996. Booklet, 48 pp. \$6.95. Item # 136808

**Coping With A Loved One's Disease: A Guide for Caregivers** (approved 2005)

by R. Anders Porter (Windstorm Creative Publishing 2005). After his fiancée was diagnosed with lupus, the author began a journal that turned into a book that provides important support, encouragement and information for the partner, whether they are the primary caregiver or not. Written with humor and a simple sense of purpose, *Coping With A Loved One's Disease* is a non-technical and insightful book that offers sensible advice. Includes a cover endorsement by Henrietta Aladjem. \$12.99, 155 pages, paperback. Available from Windstorm Creative, Attn.: Full Spectrum Information Library, P.O. Box 28, Port Orchard, WA 98366, (360) 769-7174 or [www.WindstormCreative.com](http://www.WindstormCreative.com).

**Coping with Lupus Revised and Updated** (approved 2001)

by Robert Phillips, Ph.D. (Avery Publishing Company, Garden City Park, NY, 2001). This is a new revised edition of one of the most popular books for people newly diagnosed with lupus. The author provides expanded chapters and additional topics, as well as more extensive information and resources on living with lupus. Paperback, 373 pp. \$14.95. Item # 136813

**Coping With Prednisone (and other cortisone-related medicines): It May Work Miracles, But How Do You Handle the Side Effects?** (approved 1999)

by Eugenia Zukerman and Julie R. Ingelfinger, M.D. (St. Martin's Griffin Press, 1997) ISBN 0-312-19570-2. Written by world-renowned flutist Zukerman, and her sister, Ingelfinger, a specialist in pediatric nephrology and hypertension, this is a practical guide to making treatment with glucocorticoids as effective and trouble-free as possible. It includes exercises, recipes, and tips based on personal experience. Paperback, 208 pp. \$12.95.

**Diagnosis: Lupus – The Intimate Journal of a Lupus Patient**

by Marilyn Celeste Morris (PublishAmerica Press, Baltimore 2005). When the author was suddenly confronted with symptoms of joint pain and extreme fatigue, she undertook an intensive search to understand what eventually would be diagnosed as systemic lupus erythematosus. Through the pages of her intimate daily journal she takes the reader on a journey, from chronic joint pain, frustration, anger and grief for her former self, to her current state of remission. Far from being a list of complaints, the author's pages reveal her unexpected spiritual growth and gratitude for life itself. In addition to this book the author has written both fiction and memoir. Paperback, 216 pp., \$19.95

**Disability Handbook For Social Security Applicants Seventh Edition** (approved 2008)

This brand new 7<sup>th</sup> edition of PDS Disability Workbook is an invaluable guide to understanding and navigating the Social Security Disability Insurance (SSDI) system. Used by thousands of people who have needed help filling out and filing disability insurance claims, the 136-page workbook includes an appendix with the 2008 changes to the SSDI regulations. The text includes chapters on what SSDI is, how the application process works, how to prove disability, and how to appeal an unfavorable SSA decision. The workbook also has work sheets, a "frequently asked questions" section, information on various Social Security Administration publications, and a section on what happens after you win benefit, including: overpayments, disability reviews, and returning to work. Compiled and written by Douglas Smith, Attorney at Law and produced by Physicians' Disability Services, Inc. (2008) 136 pp. Item # 136815

**The Fibromyalgia Help Book** (approved 1998)

by Jenny Fransen and I. Jon Russell (Smith House Press, 1997) ISBN 0-961522-14-3. Paperback, 239 pp. \$18.95. To order call toll-free (888) 220-5402.

**Finding The Way Home: A Compassionate Approach to Illness** (approved 1999)

by Gayle Heiss (QED Press, Fort Bragg, CA 1997) ISBN 0-936609-354. This book of thoughtful reflections on living with chronic illness is based on the author's personal experiences of living with Sjogren's Syndrome, and on discussions with hundreds of people who have attended her weekly support groups. Hardcover, 288 pp., \$24.95.

**For Inquiring Teens With Lupus: Our Thoughts, Issues & Concerns** (approved 2003)

Created and published by Hospital for Special Surgery Charla de Lupus (Lupus Chat) Program, New York City, NY, 2003. Illustrated in neon-bright colors, This booklet discusses subjects that matter to teens in language they can relate to, such as what lupus really is, how to share feelings with family and friends, changes in body and mood, and what the future may bring. Above all it offers encouragement and the power of positive thinking. Made possible by the generous support of Rheuminations, Inc. Booklet, 20 pp., free. Call (866) 812-4494 for ordering information.

**Get to Sleep: How to Sleep Well...Despite Lupus**

by Robert Phillips, Ph.D. Balance Enterprises, Inc., 1995. This helpful guide gives suggestions and tips on how to improve your sleep when you have the chronic pain that often accompanies lupus and other musculoskeletal diseases Spiral-bound, 14 pp. \$7.95. Item # 136809

**Guarded Prognosis: A Doctor and His Patients Talk About Chronic Illness and How to Cope With It (approved 1999)**

by Michael Lockshin, M.D. (Hill & Wang Publishers, a division of Farrar, Strauss and Giroux, 1998). A complicated disease like lupus often can bring patients into contact with all segments of the medical care system. Drawing on some 35 years of medical experience, rheumatologist Lockshin writes sympathetically of patients who need long-term, expensive care, and whose problems may require speedy diagnosis and treatment by specialists. Paperback, \$24.00.

**Handout on Health: Systemic Lupus Erythematosus**

Published by the National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases. Write to NAMSIC/NIH, 1 AMS Circle, Bethesda, Maryland 20892. 1997. *Free*. Ask for Publication Number 97-4178.

**House Calls: How we can all heal the world one visit at a time (approved 1999)**

by Patch Adams, M.D. (Robert D. Reed Publishers, San Francisco, CA, 1998) ISBN 1-885003-18-8. 120 cartoons. With a forward by actor and comedian Robin Williams (the star of the movie based on this book) and cartoons by nationally syndicated artist Jerry Van Amerongen, this primer on wellness includes tips for visiting loved ones, tips that are essential to the healing process, how to be a good doctor and how to be a good hospital patient. Paperback, 176 pp, \$11.95.

**Informed Consent: The Consumer's Guide to the Risks and Benefits of Volunteering for Clinical Trials (approved 2004)**

by Kenneth Getz and Deborah Borfitz (CenterWatch, a division of Thomson Healthcare, Inc., Boston, MA, 2002). This book looks specifically at the type of research that involves active participation of people to test the safety and effectiveness of new medical treatments. Chapter topics include why people participate, historical events that have shaped protection for human subjects, and vulnerable populations. The book's foreword is by Paul Gelsinger, whose son, Jesse, died in the course of a gene therapy clinical trial in September 1999. Paperback, 306 pp. with appendices, \$16.95.

**Inside Fibromyalgia** (approved 2001)

by Mark J. Pellegrino, M.D. (Anadem Publishing, Inc., Columbus, OH, 2001) ISBN-1-890018-36-8) Anyone interested in living better with this complex disease should enjoy this comprehensive book. The author's special understanding of what really works, and what doesn't, comes from his personal experience of having fibromyalgia himself. The book is written with compassion and humor, and will help readers develop their own plan for healing. For ordering information call toll-free (800) 633-0055. Paperback, 347 pp. \$24.50.

**It's Not Just Growing Pains: A Guide to Childhood Muscle, Bone, and Joint Pains, Rheumatic Diseases, and the Latest Treatments** (approved 2004)

by Thomas J. A. Lehman, M.D., FAAP, FACR (Oxford University Press, New York, NY, 2004) ISBN 0-19-515728-1. In this comprehensive resource guide for parents and professionals, the author offers easy-to-understand information on the causes, symptoms, tests and treatments for a variety of rheumatic diseases and childhood pain. Hardcover, 418 pp., \$35.00. Item # 136811

**Jakoter Personal Health Organizer** (approved 2005)

by Laura Heuer (Jakoter Health Organizers). This three-ring binder is designed to help keep track of medical papers and records – a very important task when living with a chronic and complex illness like lupus. The tabbed sections include medical histories of family members, allergies, emergency contacts, appointments, doctors' contact information, and much more. Extra binder pages are available and divider tabs can be customized. 75 pp. plus 13 pocket pages, \$34.95. Also now in a flash stick format. Order online at [www.jakoter.com](http://www.jakoter.com) or by calling (847) 7119-2-54.

**Journey Beyond Diagnosis: Support During and After Illness for Survivors and Those Who Love and Care for Them** (approved 2006)

by Greg Pacini (Reedy Press, 2005) The author, a licensed counselor and certified group psychotherapist for 25 years, has specialized the past 15 years in support of the chronically and terminally ill, their caregivers and the medical professionals who serve them. Using a journey as his analogy, the book discusses how to deal with adversity along the way. Interspersed throughout the narrative are eleven rest stops: step-by-step techniques for making the journey more comfortable. One reviewer says, "The focus of Journey Beyond Diagnosis is on emotional well-being after diagnosis with a chronic condition. Overall the book is thought-provoking, providing insight on how to live in a state of 'awareness,' being mindful of one's feelings but not overwhelmed by them. Since the book covers the whole spectrum of illness – from diagnosis to death – patients may want to read only those sections of the book that deal with their particular stage of illness." 244 pp., \$19.95 paperback.

**The Language of Water** (approved 2004)

by Jude Clarke (Thistledown Press, Ltd., Saskatoon, Saskatchewan, Canada, 2002) ISBN 1-894345-44-4. The author's graceful poignant autobiography is accompanied by full-color reproductions of her paintings which reflect her personal growth during her struggle

with lupus. The book also is a compelling work of autobiography that examines the intricate issues of women's health and creative expression. Paperback, 278 pp., \$19.95.

**Living Well, Despite Lupus!** (approved 1996)

by Robert Phillips, Ph.D. (Balance Enterprises, Inc., 1996). This booklet offers 204 surefire strategies for taking charge of your life to enable you to live well. Booklet, 50 pp. \$7.95. Item # 136960

**Living Well With a Hidden Disability** (approved 1999)

by Stacy Taylor, M.S.W., L.C.S.W. and Robert Epstein, Ph.D. (New Harbinger Publications, 1999). Written for people with disabling conditions and the medical professionals who care for them, these strategies for growth, health, and happiness reassure readers that they aren't alone and provide tips for dealing with pain and confusing emotions. Paperback, 295 pp, \$15.95.

**Living With Lupus: The Complete Guide, Second Edition Revised and Updated** (approved 2005))

by Sheldon Paul Blau, M.D. and Dodi Schultz (De Capo Lifelong Books, 2004). In this new edition, authors Blau and Shultz discuss medications and therapies, current research directions, and potential disease complications. The book offer tips for day-to-day coping, plus information on dealing with decisions on pregnancy and hormone replacement. Lupus in children and teens, possible causes of the disease, and the doctor-patient relationship also are covered. The book contains a glossary of terms and a resource section. \$16, 262 pages, paperback. Available at local bookstores.

**Loopy Lupus Helps Tell Scott's Story** (approved 2002)

(Lupus Foundation of America, 2002). This book, written by Scott and his third-grade class, explains what it's like to live with lupus. The story is told in Scott's voice, for children reading the book, and in the voice of Loopy Lupus, for parents, teachers, and caregivers. Paperback, 34 pp. \$8.95. Item # 136802-001 Hardcover Item # 136802-002

**Lupus: A GP Guide to Diagnosis** (approved 2001)

Compiled by Yvonne Norton. 2000. This excellent booklet was created especially for health practitioners in Great Britain and contains certain phrases more common to the United Kingdom. It offers physicians and nurses valuable information on the many complex issues surrounding lupus. Booklet, 32 pp. Available through Lupus UK, St. James House, 27-43 1, Eastern Road, Romford, Essex RM1 3NH United Kingdom. Phone: 44-0-1708-731-251; Fax: 44-0-708-731-252; E-mail: headoffice@lupus-uk.freemove.co.uk.

**LUPUS: A Patient's Guide to Diagnosis, Treatment, and Lifestyle** (approved 2008)

by Ana Quintero Del Rio, M.D., M.P.H, F.A.A.P. (Hilton Publishing, 2007) Dr. Quintero del Rio is a pediatric rheumatologist who practices at San Jorge Children's Hospital and teaches at the Poce School of Medicine in Santurce, Puerto Rico. In this book she discusses at length how lupus is detected, its many symptoms and complications, the

most successful and current treatments available, and ongoing research. Personal stories throughout lend a warm touch and illustrate how people with lupus are crafting solutions to the many challenges of living with this complex and unpredictable disease. The Patient Resources chapter includes information on finding the proper physicians, patients' rights, Internet sites on lupus and related disorders, patient advocacy groups, prescription medication assistance programs, international lupus groups, and selected references. \$16.95 hardcover, \$12.50 paperback, 188 pp.

**Lupus and Osteoporosis: What You Need to Know** (approved 2003)

(Lupus Foundation of America, 2003). This booklet describes osteoporosis and the special risks of bone density loss caused by lupus itself and by the corticosteroids commonly taken for the inflammation associated with lupus. Includes glossary and resource list. Booklet, 30 pp. \$2.50. Item # 136818

**Lupus: A Patient Care Guide for Nurses and Other Health Professionals Revised Third Edition (2006)** (approved 2001)

Published by the National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases. Write to NAMSIC/NIH, 1 AMS Circle, Bethesda, Maryland 20892. Free. Ask for Publication Number 06-4262.

**Lupus Q&A: Everything You Need To Know** (revised edition of *Lupus: Everything You Need To Know*, approved 2004)

by Robert G. Lahita, M.D., Ph.D. and Robert H. Phillips, Ph.D. (Avery Publishing Company, Garden City Park, NY: 2004). This book has been one of the most popular books on lupus since it was first published in 1998. The text covers diagnosis, symptoms, treatment, medication, and the impact of lupus. Written in an easy-to-read question and answer format, this book combines the vast experience of a renowned lupus physician-researcher and a highly experienced psychologist. Paperback, 240 pp. \$19.95. Item # 136814

**Many Shades of Lupus** (replaces *What Black Women Should Know About Lupus*) (approved 2001)

Published by the National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2001. Write to NAMSIC/NIH, 1 AMS Circle, Bethesda, Maryland 20892. Free. Ask for Publication Number 01-4958.

**Meeting the Challenge: Living with a Chronic Illness** (approved 1998)

by Audrey Kron. 1998. To order, write to: Audrey Kron, 7466 Pebble Lane, West Bloomfield, MI 48322. ISBN 0-963387-715. Paperback, \$19.00 (includes S&H).

**Memory Minder Personal Health Journal** (approved 1999)

This book is useful for people with any type of chronic health condition. Designed as a health diary, this journal format makes it easy to document the many factors that contribute to a chronic illness. Spiral-bound, \$14.95. For ordering information call toll-free (800) 888-3392, or write to Memory Minder Journals, P.O. Box 23108, Eugene, OR 97402. Call for prices on orders of more than 10 copies.

**The Monster Under the Bed: Child Rearing When a Parent is Chronically Ill Revised Edition** (approved 2007)

by Barbara Butler, 1990. This book was written by a mother with lupus for other parents who are trying to cope with raising children and living with a chronic and often debilitating illness. The author is one of the founding members of the Lupus Foundation of America and started the LFA, Missouri Chapter. Paperback, 32 pp., \$4.00 Item # 136819

**New Hope for People With Lupus** (approved 2002)

by Theresa Foy DiGeronimo, M.Ed. (Prima Publishing, (a division of Random House, Roseville, CA, 2002) Subtitled "Your Friendly Guide to the Latest in Traditional and Complementary Solutions," this book discusses new research results, the mind-body connection, and creating a healthier future. The author, an adjunct professor at William Paterson University in New Jersey, also has written *New Hope for People With Fibromyalgia*. Paperback, 284 pp. \$18.95.

**Numb Toes and Aching Soles: Coping With Peripheral Neuropathy** (approved 2001)

by John A. Senneff. (MedPress Publishers, 1999). Many people with lupus and Sjogren's Syndrome also suffer from peripheral neuropathy, a painful and sometimes disabling nerve disorder. Written from a patient's point of view, this reader friendly guide discusses PN in non-technical terms. Hardcover, pp, \$29.95. Paperback, 300 pp, \$19.95. Available at local bookstores or from the publisher by calling toll-free (888) 633-9898.

**Peace in the Storm: Meditations on Chronic Pain and Illness** (approved 2006)

by Maureen Pratt, co-author of *Taking Charge of Lupus* (Doubleday, 2005) The author, who lives with lupus, fibromyalgia, Grave's disease and vasculitis, is intimately aware of the toll that chronic pain and illness can take on patients and their families. In this practical and spiritual guide, she uses a combination of passages from the Bible and her own insights to provide help on issues such as dealing with isolation, finding the right doctor, rejoicing in the happiness of others, and mourning the loss of health. Written with honesty and understanding, this book can help readers to identify their own spiritual and physical needs. In one reviewer's words, "Readers can find valuable daily inspiration and encouragement while leisurely reading through *Peace in the Storm*. It provides good food for thought and lifts a patient's outlook on lupus." 321 pp., \$12.95 paperback.

**Power Nutrition for Your Chronic Illness: A Guide to Shopping, Cooking and Eating to Get the Nutrition Edge (Paperback)** (approved 1998)

by Kristine Napier. (Macmillan Publishing, New York, NY, 1998) ISBN 0-02-862059-3. This easy-to-read book provides 200 easy recipes that put nutrition theory into action. Specific diseases covered are: Alzheimer's; arthritis (osteoarthritis, rheumatoid, fibromyalgia); asthma; epilepsy; HIV/AIDS; lupus; multiple sclerosis; myasthenia gravis; Parkinson's Syndrome; psoriasis; and Sjogren's Syndrome. There is also an entire section on nutrition for commonly used medications on a drug-by-drug basis, as well as

information on nutrition for healing after surgery, supplements, and how to eat to prevent additional health problems such as obesity and osteoporosis. Paperback, 416 pp. \$19.95.

**Questions & Answers About Sjogren's Syndrome** (approved 2001)

Published by the National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2001. Write to NAMSIC/NIH, 1 AMS Circle, Bethesda, Maryland 20892. Free. Ask for Publication Number 01-4861.

**Regrets & Roses-A Memoir** (approved 2004)

by Violet Mazzola (Fairway Press, Lima, OH, 2002) ISBN 0-78-802046-3. This is an inspiring and courageous memoir of how three generations of women—a grandmother, a mother with lupus, and a daughter who donated one of her kidneys to save her mother's life—refused to let lupus conquer their family. The book depicts the realities of medical treatment, with both good and bad results. It also makes a strong case for patients to accept responsibility for their medical care. Paperback, 172 pp, \$14.95.

**SALUD! A Latina's Guide to Total Health revised edition**

by Jane Delgado, Ph.D. (HarperCollins Publishers, 2002). Featuring new resource lists of relevant books and new hotlines and organizations that can help keep Latinas informed and healthy, this revised edition of SALUD! addresses with great sensitivity the special concerns of Latinas—physiological, cultural, and spiritual. Dr. Delgado is president and CEO of the National Alliance for Hispanic Health. Paperback, 396 pp, available in both English and Spanish. \$19.95.

**Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill Revised and Updated**

by Cappy Capossela and Sheila Warnock (Fireside Book/Simon & Schuster New York 2004). Taking on responsibility for short or long-term care for a loved one who is seriously ill can be overwhelming and confusing. In this book the authors explain the concept of developing "caring networks" so that the work that needs to be done is spread among friends, neighbors, and family members. This lessens the stress on the primary caregiver and provides peace of mind to the patient. The book also includes sample forms and numerous checklists that help provide both practical advice and reassurance. Suzanne Mintz, president/founder of the National Family Caregivers Association, called *Share the Care* "one of the best books ever written to help family caregivers." Paperback, 348 pp., \$14.00)

**Sick and Tired of Feeling Sick and Tired** (approved 2001)

by Paul Donoghue, Ph.D. and Mary Siegel, Ph.D. New York: W. W. Norton Publishing, 2000. ISBN 0-393320-65-0. This new edition includes a new introduction, a list of Web sites. And the inclusion of arthritis in the list of illnesses that is representative of "invisible chronic illness." Paperback, 304 pp. \$8.95. Item # 136816

**The Sjogren's Syndrome Survival Guide** (approved 2004)

by Teri P. Rumpf, Ph.D. and Katherine Morland Hammitt (New Harbinger Publications, Inc., Oakland, CA. 2003). Rumpf, a clinical psychologist, and Hammitt, past president of

the Sjogren's Syndrome Foundation, both live with Sjogren's Syndrome. Their book provides the latest research, treatment methods and new therapies, as well as self-help strategies. 235 pp., \$15.95. Available through the Sjogren's Syndrome Foundation Web site, [www.sjogren's.org](http://www.sjogren's.org), or by calling toll-free (800) 475-6473.

**Special Kids Need Special Parents: A Resource for Parents of Children With Special Needs.** (approved 2004)

by Judith Loseff Lavin (Berkley Publishing Group, a division of Penguin Putnam, 2001)  
When the author needed information on pediatric hospitals and children with special needs, she found resources to be scarce. Her book gives readers advice, encouragement and comfort through interviews with healthcare professionals, nationally recognized authorities, and families of children with a variety of special needs. paperback, 319 pp., \$13.95

**Sticky Blood Explained – Hughes Syndrome** (approved 2004)

by Kay Thackray (Braiswick/Author Publishing Ltd., Felixstowe, Suffolk, UK, 2002).  
Despite having been described in clinical articles since the early 1980s, the antiphospholipid syndrome is still under-diagnosed by physicians. Also known as Hughes Syndrome and APS, the features of this distinct syndrome include headaches, miscarriages, blood clots, strokes, and the effect on platelets that earn it the term "sticky blood." Aimed at patients and doctors alike, this book is written by a patient in clear language from her own experiences. Paperback, 133 pp., £7.95, approx. \$16.00; order through website: <http://www.author.co.uk/thackray/>.

**Stress Management Handbook: Strategies for Health and Inner Peace**

by Lori A. Leyden-Rubenstein, Ph.D. (Keats Publishing, New Canaan, CT, 1998) ISBN 0-87-983794-2. To order call (800) 540-9440. In her latest book, the author reveals how she helps her clients create their own emotional, physical and spiritual wellness through the use of guided imagery, inner voice work and psychotherapy that is goal-oriented, yet nurturing and humorous. Paperback, 208 pp, \$14.95.

**Successful Living With Lupus: An Action Workbook, New and Revised 2005 Edition** (approved 2000)

by Robert H. Phillips, Ph.D. Balance Enterprises, Inc. 2000. This workbook is written in Dr. Phillips' usual friendly manner and offers plans to improve your life with lupus. Paperback, 73 pp. \$10.00. Item # 136810

**Taking Charge of Lupus: How to Manage the Disease and Make the Most of Your Life** (approved 2003)

by Maureen Pratt and David Hallegua, M.D. (New American Library, a division of Penguin Putnam, Inc., 2002). Lupus is an unpredictable disease with no known cure. That is why lupus patient Pratt and rheumatologist Hallegua wrote this book of trial-and-error tips for managing lupus daily. Topics include coping with the side effects of medications, picking the right doctor, adapting your home, and surviving financial burdens. Paperback, \$14.00. Available at bookstores.

**Talking With Your Kids About Serious Illness in the Family** (approved 2004)  
by Lisa O. Engelhardt and Lyn Sontag, Psy.D. (One Caring Place/Abbey Press, 1998). This short booklet offers guidance and support to parents, teachers and other caring adults who need to communicate to children ages 4-7 and 8-12 about illness of the family. 75 cents, 6 pages. Available from One Caring Place, Abbey Press, St. Meinrad, IN 47577, (800) 325-2511 or [www.carenotes.com](http://www.carenotes.com).

**¿Tengo lupus? Do I Have Lupus?** (approved 2003)  
This booklet from the National Institute of Arthritis and Musculoskeletal and Skin Diseases contains general information about lupus. It describes what lupus is, the different forms of lupus, its symptoms, causes, risk factors, diagnosis, and treatment. It presents ways to cope with lupus. Information is also provided on current research. Up to 25 books per order may be obtained free of charge through the NIAMS Clearinghouse online at <http://catalog.niams.nih.gov/index.cfm>. Search for NIH Publication No. 03-5321.

**The Lupus Book: A Guide for Patients and Their Families** Third Edition (approved 2005)  
by Daniel J. Wallace, M.D. (Oxford University Press, 2005). This revised and expanded edition explains a complicated disease in easy-to-understand terms and is suitable for the motivated patient wanting a concise, practical overview of their disease. It also contains new sections relating to disability, economic impact of the disease, biologics and other new drug treatments, clinical measures of disease activity, clinical trial methods, and proactive treatment strategies, while sections relating to inflammation and the causes of lupus have been significantly updated. Hardcover, 271 pp. \$19.95. Item # 136812

**The New Sjogren's Syndrome Handbook** Revised and Expanded Third Edition (approved 2005)  
Edited by Daniel J. Wallace, M.D. (Oxford University Press, 2005). Considered the definitive guide for people living with Sjogren's syndrome as well as the health professionals who are treating them, this third edition contains chapters by the leading rheumatologists in the country. Topics include where and how the body can be affected by Sjogren's, disease outcomes, management of symptoms, and future directions. Appendices include resources, products that may be useful, and a glossary. Hardcover, 265 pp., \$30.00 at area bookstores.

**Total Relaxation: Healing Practices for Body, Mind & Spirit** (approved 2001)  
by John R. Harvey Ph.D. (Kodansha America Press, Inc. New York, 1998). The author, who is the director of the Psychology Department of Allied Services Medical Rehabilitation Hospital in Scranton, PA, draws on years of experience in treating patients worn out by stress. He offers a selection of relaxation techniques organized into five different categories: muscular, autonomic, emotional, mental, and spiritual. Paperback book, 185 pp., with CD. \$20.00.

**We Are Not Alone: Learning To Live With Chronic Illness**

by Sefra Kobrin Pitzele (Workman Publishing, New York, 1987). The author offers thoughts and strategies for coping with chronic illness based on her personal experiences with lupus. A long-time favorite book to share with a loved one living with lupus. Paperback, 315 pp. \$9.00. Item # 136817

**What Chinese Americans and Their Families Should Know About Lupus** (approved 2003)

Created and produced by Hospital for Special Surgery's LANtern (Lupus Asian Network) Program, New York City, NY, 2003. Written in a culturally sensitive way, the goal of this booklet is educate the Chinese community about lupus, how it is treated, where to find support, and where to go for more information. Made possible by the generous support of Rheuminations, Inc. Bilingual booklet, 20 pp., no cost. Call (866) 812-4494 for ordering information.

**When Mom Gets Sick** (*temporarily out of print*)

by Rebecca Samuels, 1992. This charming little book about life with a mom who has lupus was written and illustrated by a nine-year-old girl. Paperback, 27 pp. \$6.95.

**Wild Woman's Guide To Living With Illness** (approved 2003)

by Cindy Coney. (Mendez Foundation, Tampa, FL, 1999) ISBN 0-96-275534-6. Spiral-bound journal 100 pp. & three audiocassettes. \$59.95. To order call (800) 750-0986.

**Women and Autoimmune Disease: The Mysterious Ways Your Body Betrays Itself**

by Robert G. Lahita, M.D., Ph.D., FACR, FACP and Ina Yalof (Regan Books; reprint edition July 2005). Robert Lahita (editor of the *Textbook of Autoimmunity*, the seminal work on the subject for medical professionals; editor of the recently published fourth edition of the standard textbook *Systemic Lupus Erythematosus*; and co-author of the popular book, *Lupus Q&A: Everything You Need to Know*) is a well-known name in the lupus field. In his newest book he discusses how autoimmune diseases afflict women, who make up 75% of cases nationwide. With medical writer Ina Yalof, Dr. Lahita draws on research and case studies to identify 16 conditions that have been categorized as autoimmune diseases (he includes chronic fatigue syndrome, though its cause remains uncertain). Among the information he presents are the symptoms, causes and possible treatments for these often debilitating conditions. Publishers Weekly says, "This clearly written text should be extremely useful to people with these difficult ailments, their families and caregivers." Hardcover, 304 pp., \$25.95.

**You Don't Look Sick! Living Well With Invisible Chronic Illness** (approved 2006)

by Joy H. Selak and Steven S. Overman, M.D., M.P.H., F.A.C.R. (The Haworth Press, Inc. 2005). This book tells the true story of one woman's journey through three stages of chronic illness—getting sick, being sick, and living well—and includes her physician's commentary in each section. Designed for individuals in the beginning stages of a chronic illness, the book's stories, dialogue, humor, and examples will also be

illuminating for caregivers and loved ones. 144 pp., \$14.95 paperback; \$29.95 hardcover

## CD-ROMs

### **Butterflies and Sunshine**

Designed for Macintosh or PC with 8 meg of RAM. This program is used to enhance information given to patients of all ages by physicians, nurses, and educators, about systemic lupus erythematosus. Its final segment is a series of review questions. An incorrect response to a question directs the viewer to the appropriate section for review. Viewing time: 23 minutes. \$12.95 or \$11.95 for 2 or more, includes S&H. The CD may be ordered through W.S. Interactive Education, AMFAC Building, Hawaii Tower, 745 Fort St., Suite 1501, Honolulu, HI, 96813, or by phone/fax at (808) 534-0335. Please make checks payable to Kapi'olani Medical Center for Women and Children.

### **Lupus and Other Related Information for You and Your Patients** (approved 2007)

Produced by the National Institute of Arthritis and Musculoskeletal and Skin, this CD-ROM contains print-friendly PDF files of selected patient education brochures, professional educational resources, including information from the updated *Lupus Nurses' Guide* (3rd edition), and Web links to numerous useful resources from the National Institutes of Health, other Federal agencies, and nonprofit organizations. The information will be valuable to lupus health professionals, patients and family members, faculty at health profession institutions, and nonprofit organizations serving individuals with lupus and their families. Free copies may be ordered through the NIAMS Clearinghouse toll-free line, (877) 22-NIAMS (1-877-226-4267), or [niamsinfo@mail.nih.gov](mailto:niamsinfo@mail.nih.gov), or visit <http://www.niams.nih.gov>.

## DVDs

### **"Tai Chi for Arthritis"** (approved 2004)

by Dr. Paul Lam (Wellspring Media, 2002.) This multi-language edition is available in English, Spanish, French, and Mandarin. Tai Chi is believed by many to be one of the most effective ways to improve health and fitness, and to promote relaxation. This program, part of the "Tai Chi Self-Teaching Beginner Series," is designed especially for people with arthritis and other conditions that affect the joints. Approx. 80 minutes, \$24.95; with illustrated paperback handbook, 62 pages, \$10.00. Order from the company's Web site, [www.taichiproductions.com](http://www.taichiproductions.com) or write to U.S. East Acton Video, P.O. Box 3102, Rancho Cordova, CA 95741-3102.

### **"The Right Moves for Lupus"** (approved 2004)

If lupus has you on the sidelines instead of in the middle of the action, this new low-impact exercise program may be "just right" for you. Through the guidance of a licensed A.C.E. instructor who also has lupus, this program can help get you moving in the

comfort of your own home. Available from the LFA, Piedmont Chapter by calling (704) 375-8787, or on the chapter Web site, [www.lupuslinks.org](http://www.lupuslinks.org).

## **OTHER**

### **Talking Books for Blind and Visually Handicapped**

The Library of Congress, National Library Service for the Blind and Physically Handicapped, has a number of items on lupus in Braille or audiocassette for loan through each state's "Talking Book Program." For more information, contact the National Library Service for the Blind and Physically Handicapped, The Library of Congress, Washington, DC 20542. Call toll-free: (800) 424-8567 or (202) 707-5100, TDD: (202) 707-0744; Fax: 202/707-0712; E-mail: [nls@loc.gov](mailto:nls@loc.gov); or visit the website at [www.loc.gov/nls](http://www.loc.gov/nls).

### **MedicTag** (approved 2007)

MedicTag™ is the best way to store medical information for easy transport to doctors' appointments, hospital stays, or trips away from home. MedicTag is a USB flash disk (flash stick). It comes with template forms installed; you simply fill in as much or as little information as you need. Most doctor's offices have PC compatible computers with USB ports, so the MedicTag can plug right in. In addition, any emergency service with access to a PC or laptop can use them. The flash disk's system requirements are: Windows XP \*, a USB 1.0/1.1/2.0 port, access to Microsoft Word, and an IBM Compatible PC or Notebook computer. For more information, visit the Jakoter health Organizers Website at [www.jakoter.com/medic-tag.htm](http://www.jakoter.com/medic-tag.htm), call Jakoter, LLC at 847-719-2054, or send an e-mail to [info@jakoter.com](mailto:info@jakoter.com). Cost is \$39.95 each.

## **VIDEOTAPES**

### **"Lupus, An Issue for the African-American Community"**

Available from the LFA Marcy Zitron Chapter, 6161 Busch Blvd., Suite 76, Columbus OH 43229 or call (614) 755-5077. 28-minute VHS. 1993.

### **"Lupus: Insights, Emotions, Encouragements"**

Available from the LFA Marcy Zitron Chapter, 6161 Busch Blvd., Suite 76, Columbus OH 43229 or call (614) 755-5077. 54-minute VHS. 1992.

### **"Living With Lupus: A Practical Guide for Living, Looking and Feeling Better"**

Available from the LFA Marcy Zitron Chapter, 6161 Busch Blvd., Suite 76, Columbus OH 43229 or call (614) 755-5077. 28-minute VHS. 1997.

### **"Stories of Lupus"**

by Marcia Urbin Raymond and Karin Mellberg. 27-minute VHS. 1999. \$14.95. Item # VID0002

### **"Target Awareness"**

Interviews with Dr. Robert Katz and Dr. Robert Lahita. 6-minute VHS. 1994. \$5.95. Item # VID0001

**“Voices of Lupus”**

For price and ordering information, write to Films for the Humanities & Science, P.O. Box 2053, Princeton NJ 08543 or call (800) 257-5126. 28-minute VHS.

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