

# SCLERODERMA FOUNDATION TRI-STATE, INC. CHAPTER RESOURCE LIBRARY

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## CONTACT OUR OFFICE:

**E-mail:** [sdtristate@sclerodermatristate.org](mailto:sdtristate@sclerodermatristate.org) | **Phone:** 800-867-0885 or 607-723-2239

**Write:** Scleroderma Foundation, Tri-State Chapter, 59 Front Street, Binghamton, NY 13905

Many recent educational forums are available for viewing on-line at: [www.sclerodermavideo.com](http://www.sclerodermavideo.com)

## BOOK LIBRARY

UPDATED 09/2017

RESOURCE #	DESCRIPTION
100	THE SCLERODERMA BOOK: GUIDE FOR PATIENTS & FAMILIES, Maureen Mayes, MD
101	CUTANEOUS MANIFESTATIONS OF RHEUMATIC DISEASE (Textbook), 1996, Edited By Richard D. Sontheimer & Thomas T. Provost
102	THE SJOGREN'S SYNDROME HANDBOOK, Edited by Elaine K. Harris (1989)
103	THE BEST OF THE BEACON, Edited By Marie Coyle
104	SYSTEMIC SCLEROSIS (Textbook), Edited By Philip Clements, MD & Daniel Furst, MD (1996)
105	THE ARTHRITIS BREAKTHROUGH, Henry Scammel (1993)
106	NETTER'S GASTROINTESTINAL ANATOMY & MOTILITY, Selections From The Netter Collection Of Medical Illustrations, Frank H. Netter, MD
107	SCLERODERMA: THE FIRST YEAR, Karen Gottesman
108	A MEMOIR: A PLACE TO GO: HOW SCLERODERMA CHANGED MY LIFE, Maureen Taylor
109	MANGOSTEEN DESK REFERENCE: 61 Conditions That Respond To Mangosteen, Dr. K. Finsand
110	JOURNEY BEYOND DIAGNOSIS: Support During & After Illness For Survivors & Those Who Love & Care For Them, Greg Pacini
111	GUIDE TO ALTERNATIVE THERAPIES, The Arthritis Foundation, Judith Horstman (1999)
112	MIRACLE MEDICINE HERBS, Richard Lucas (1991)
113	SUCCESSFUL LIVING WITH SCLERODERMA: A Balance Strategy Guidebook, Robert H. Phillips, PhD (2002)
114	SCLERODERMA: Caring For Your Hands & Face, Jeanne Melvin, MS, OTR, FAOTA, The American Occupational Therapy Assoc., Inc. (1994)
115	PDR FOR NUTRITIONAL SUPPLEMENTS, Physician Desk Reference (2000)
116	PRESCRIPTION FOR NUTRITIONAL HEALING, James Balch, MD & Phyllis Balch, MD (1997)
117	THE ESSENTIAL ARTHRITIS COOKBOOK: Kitchen Basics, The Arthritis Center (1995)
118	FOODS THAT FIGHT PAIN, Neal Barnard, MD (1998)
119	EATING FOR ACID REFLUX, Jill Sklar & Annabel Cohen (2003)
120	I-CAN'T-CHEW COOKBOOK, J. Randy Wilson (2003)
121	SHARED FAVORITES, Scleroderma Cookbook, Scleroderma Federation (1993)
122	WELLNESS MADE EASY, 101 Tips For Better Health, University of CA Berkeley Wellness Letter
123	HEALING WITH VITAMINS, Prevention Health Book (1996)

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- 111 GUIDE TO ALTERNATIVE THERAPIES, THE ARTHRITIS FOUNDATION, Judith Horstman (1999)
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- 122 WELLNESS MADE EASY, 101 TIPS FOR BETTER HEALTH, University Of CA Berkeley Wellness Letter
- 123 HEALING WITH VITAMINS, Prevention Health Book (1996)
- 124 NATURAL HEALING REMEDIES 1999, Prevention Health Book (1999)
- 125 EVERYBODY'S GUIDE TO HOMEOPATHIC MEDICINES, Stephen Cummings, MD & Dana Ullman, MPH
- 126 BLENDED MEDICINE: THE BEST CHOICES IN HEALING, Michael Castleman (2000)
- 127 HEALING, Francis MacNutt (1974)
- 128 THE HEALING COMPANION (For Caregivers, Support Group Leaders, etc.) Jeff Kane, MD (2001)
- 129 AND HOW ARE WE FEELING TODAY?: The Impatient Patient's Hospital Survival Guide (Comic Relief), Kathryn Hammer (1993)
- 130 HELPFUL HINTS for living with Scleroderma, Scleroderma Federation
- 131 SICK & TIRED OF FEELING SICK & TIRED: Living With Invisible Chronic Illness, Paul Donoghue, PhD & Mary Siegel, PhD (1992)
- 132 HOW TO SURVIVE THE LOSS OF A PARENT (A Guide For Adults), Lois Akner, CSW, With Catherine Whitney
- 133 ADVANCED LUNG DISEASE 101: A PATIENT'S GUIDE, Arunabh Talwar, MD
- 134 SUCCESSFUL FUNDRAISING 2ND EDITION: A Complete Handbook For Volunteers & Professionals, Joan Flanagan, (2000)
- 135 HOW DOCTORS THINK, Jerome Groopman, MD, (2007)
- 136 SCLERODERMA COPING STRATEGIES, B. Bianca Podesta (2011)
- 137 THE SECOND JEWISH BOOK OF WHY, Alfred J. Kolateh, (1985)
- 138 CHASING THE CURE, Doris Razo (2008)

## BOOK LIBRARY

- 139 TAKING CHARGE How to Master the Eight Most Common Fears of Long Term Illness, Pollin/Golanit (1994)
- 140 A BRIEF HISTORY OF WOUND HEALING, Ortho McNeil Pharmaceuticals (1998)
- 141 BE YOUR BEST ADVOCATE, Jan Gnall, (2009)
- 142 IF YOU HAVE TO WEAR AN UGLY DRESS, LEARN TO ACCESSORIZE! Linda McNamara, RN, MBA & Ka-ren Kemper, MSPH, PhD (2011)
- 143 THE SJOGREN'S BOOK, Sjogren's Syndrome Foundation, Edited by Daniel J. Wallace, MC
- 144 YOU GOTTA EAT!, Linda Clancy Kaminski, MS, RD, CDE
- 145 BACK TO LIFE, Alicia Salzer, MD (2011)
- 146 BARRY SANDERS NOW YOU SEE HIM, Mark E. McCormick (2003)
- 147 SCLERODERMA: SURVIVING A SEVENTEEN-YEAR ITCH, Dana Lovvorn (2002)
- 148 LIVE, LAUGH, LOVE AND BE BLESSED, Sr. Anne Bryan Smollin (2006)
- 149 DISCOVERING JOY AGAIN – A Journey Through Grief (2011)
- 150 IT'S NOT JUST GROWING PAINS, Thomas J. A. Lehman, MD
- 151 PERSPECTIVES ON LIVING WITH SCLERODERMA, Mark Flapan, PhD
- 152 SCLERODERMA FROM PATHOGENESIS TO COMPREHENSIVE MANAGEMENT, John Varga, Christopher P. Denton, Fredrick M. Wigley
- 153 CLINICAL & EXPERIMENTAL RHEUMATOLOGY - CLINICAL & EXPERIMENTAL SCLERODERMA 2014, A. Tyndall, A. Tyrrell Kennedy, Y. Allanore, D. Khanna
- 154 PULMONARY HYPERTENSION PATIENT'S SURVIVAL GUIDE – Fifth Edition
- 155 HAND FUNCTION – A PRACTICAL GUIDE TO ASSESSMENT, Mehmet Tuncay Duruoz
- 156 CASE STUDIES IN SYSTEMIC SCLEROSIS, Richard M. Silver, Christopher P. Denton
- 157 ADVANCED LUNG DISEASE 101: A PATIENT'S GUIDE, Arunabh Talwar, MD
- 158 ANATOMY OF AN ILLNESS AS PERCEIVED BY THE PATIENT – REFLECTIONS ON HEALING AND RE-GENERATION, Norman Cousins
- 159 SKINNY SIZE IT – 101 RECIPES THAT WILL FILL YOU UP, Molly Morgan, RD, CDN, CSSD
- 160 DRINK YOUR WAY TO GUT HEALTH – 140 DELICIOUS PROBIOTIC SMOOTHIES & OTHER DRINKS THAT CLEANSE & HEAL, Molly Morgan, RD, CDN, CSSD
- 161 THE SKINNY RULES: THE 101 SECRETS EVERY SKINNY GIRL KNOWS, Molly Morgan, RD, CDN, CSSD
- 162 SCLERODERMA THE PROVEN THERAPY THAT CAN SAVE YOUR LIFE, Henry Scammell
- 163 A CELEBRATION OF LIFE, Andrew Botieri
- 164 HOLDING ON FOR DEAR LIFE – WHAT MY FATAL DIAGNOSIS TAUGHT ME ABOUT LIVING, Liz DeVivo
- 165 PEAKS AND VALLEYS, Spencer Johnson, MD
- 166 LUNG DISEASE 101: A PATIENT PRIMER, Arunabh Talwar, MD
- 167 ENFERMEDAD PULMONAR 101: MANUAL BASICO DEL PACIENTE, Arunabh Talwar
- 168 DOES THIS HOSPITAL GOWN COME WITH SEQUINS?, Lisa Goodman-Helfand
- 169 LET ME TELL YOU SOMETHING, DR. WILSON – WHAT I LEARNED FROM MY PATIENTS, Dr. Jeffrey W. Wilson

## DVD LIBRARY

- 243 **3/2012** - NORTH SHORE UNIVERSITY HOSPITAL ED FORUM – Scleroderma: Is It All One Disease?, Avram Goldberg, MD  
Pulmonary Arterial Hypertension & Interstitial Lung Disease in Scleroderma, Arunabh Talwar, MD
- 244 **4/2012** – UCONN HEALTH CENTER ED FORUM – Oral Health & Scleroderma, David Leader, DMD | Sjogren's Syndrome & Scleroderma, Harjinder Chowdhary, MD
- 245 **4/2012** - HSS ED FORUM – Hand Surgical Options for Patients with Scleroderma, Charles Melone, Jr, MD | Diagnostic Testing in Scleroderma, Jessica Gordon, MD
- 246 **5/2012** - ORANGE CO. HEALTH FORUM – Multiple Speakers – Topics: Preparing for Emergency Services | Massage Benefits for Autoimmune Disease  
Importance of Good Dental Hygiene Coping with Raynaud's | Taking Good Care of Your Feet | Sjogren's and Relief for Dry Eye

# DVD LIBRARY

- 247 **9/2012** - ROCHESTER, NY - Understanding Pain—What It Is, Why We Feel It & Strategies for Treatment, Amy Parkhill, PhD  
A Mindful Approach to Chronic Illness, Michael Kuttner, PhD
- 248 **9/2012** - ALBANY, NY - Making Each Moment Count, Sr. Anne Bryan Smollin, CSJ, PhD | Pulmonary Hypertension in Scleroderma, Christopher T. Dibble, MD, MS  
Vascular Disease in Scleroderma, Lee S. Shapiro, MD
- 249 **10/2012** - NIAGARA FALLS, NY – Digestive System Issues in Scleroderma, Dinesh Khanna, MD, MS | The Scleroderma Patient-centered Intervention Network (SPIN) Management of Body Image Distress, Lisa Jewett, MSc
- 250 **10/2012** – RWJ - What Makes Scleroderma Different From Other Autoimmune Diseases, Elliot Rosenstein, MD  
Scleroderma Therapies That Make a Difference, Vivien Hsu, MD
- 251 **11/2012** – HSS - Scleroderma & Cancer. . . Are They Connected?, Francesco Boin, MD, MS | Systemic Sclerosis & Sjogren's Syndrome (Separate Entities and Overlaps), Nora Sandorfi, MD | Update from the 2012 ACR Meeting, Robert Spiera, MD
- 252 **04/2013** – HSS PT. ED FORUM - Dental Issues Related to Scleroderma, Valentina Lyssova, DDS | PH and Scleroderma, Maria L. Padilla, MD
- 253 **6/2013** – YALE ED FORUM - M. Gulati, MD Update on Scleroderma Related Interstitial Lung disease, W. Fares, MD Pulmonary Hypertension in Scleroderma
- 254 **8/2013** – CARING FOR THE CAREGIVER - Speakers: MB Bobik-Kadylak | Rev. Ernie Steffensen, Maria Motsavage, RN | Dorothy Gardner, Elizabeth Hull, RN and Jerry Duvinsky, Phd.
- 255 **9/2013** – UNITY HEALTH CARE – Scleroderma Shortness of Breath: Three Things You Need to Know, Robert Dale, MD  
Scleroderma and Getting the Proper Nutrition, Joy Valvano, MS, RD, CDE
- 256 **9/2013** – ALBANY COLLEGE OF PHARMACY & HEALTH SCIENCES – Why Won't My Food Digest, Phillip Jaffee, MD  
Dental Care Issues in Scleroderma, Theodore Gialanella, DDS
- 257 **10/2013** – UCONN - Raynaud's Phenomenon & Scleroderma, Harjinder Chowdhary, MD | Scleroderma and Your Skin, Frank Santoro, MD
- 258 **11/2013** – RUTGER'S UNIVERSITY-JOINT FORUM - New Classification Criteria for Systemic Sclerosis Explained | Earlier Diagnosis-Better Outcomes, Vivien Hsu. MD  
Lung Disease and Scleroderma, Robin Lucas, MD
- 259 **11/2013** – HSS RESEARCH FORUM - Summary of the 2013 American College of Rheumatology Meeting, Robert Spiera, MD  
Stem Cell Research and Scleroderma, Robert Simms, MD | Research and Hope for Interstitial Lung Disease in Scleroderma, Erica Herzeg, MD, PhD
- 260 **4/2014** – HSS SPRING FORUM - Support, Advocacy Self Empowerment, Seth Ginsberg | What is Scleroderma & What Makes the Juvenile Form Different?, Sara Taber, MD | The Mind/Body/Spirit Connection, Mark Pettus, MD
- 261 **5/2014** – STONY BROOK FORUM - Advice on Living Well with Scleroderma: Patience, Persistence & Hope, H. Blumstein, MD  
Scleroderma and the Lung, P. Strachen, MD
- 262 **6/2014** – YALE WEST CAMPUS - Update on Scleroderma Research, E. Herzog, MD | Chronic Pain Management, Jennifer Kapo, MD
- 263 **8/2014** – NIAGARA FALLS, NY - Scleroderma Symptom Management, J. Pope, MD | Scleroderma is a Vascular Disease, L. Shapiro, MD
- 264 **9/2014** – ALBANY, NY - OTR/L Improving Flexibility in Scleroderma, Celeste Freeman | Dealing with Sleep Issues, S. Kuhar, MD  
Facing Health Challenges, Alyssa Paulsen
- 265 **9/2014** – NORWICH, CT - The Future of Scleroderma, H. Chowdhary, MD | Pulmonary Aspects of Scleroderma, T. Dahanayake, MD
- 266 **10/2014** – AFRICAN-AMERICAN HEALTH AWARENESS DAY; Rochester, NY - Scleroderma-Diagnosis, Treatment & How the Disease Differs in People of African-American Descent, V. Steen, MD | The Importance of the Caregiver, M. Richards, MS | Coping with Chronic Illness, T. Rosenberg, PhD  
Laughter is good For the Soul, R. Ray | Working Through End of Life Decisions, Rev. Robin Franklin | Meditation and Journaling, Wanda Strother
- 267 **11/2014** – RESEARCH FORUM; NY, NY - Participating in Research-How it Works & What is Out There, R. Spiera, MD | Update on Scleroderma Research -Searching for the Cause and Cure, Maureen Mayes, MD | Phototherapy and UVA1 Phototherapy Research, Heidi Jacobe, MD
- 268 **11/2014** – RESEARCH FORUM; NY, NY - Participating in Research-How it Works & What is Out There, R. Spiera, MD | Update on Scleroderma Research -Searching for the Cause and Cure, Maureen Mayes, MD | Phototherapy and UVA1 Phototherapy Research, Heidi Jacobe, MD
- 269 **4/2015** – EDUCATIONAL FORUM; HSS - Workers Compensation and Scleroderma, Victor Fusco, Esq. | Brain Function and Scleroderma, Arnold Postlethwaite, MD
- 270 **9/12/15** – EDUCATION FORUM; Albany, NY - Scleroderma Pulmonary Issues and Treatment, A. Ariel Jaitovich, MD | Scleroderma GI Issues & Treatment, Micheal Tadros, MD | Lee Shapiro, MD Scleroderma is a Vascular Disease Inside & Out
- 271 **10/10/15** – EDUCATION FORUM; Rochester, NY - Wounds: Prevention, Treatment and Healing, Toufic Rizk, MD  
Scleroderma is a Vascular Disease Inside & Out, Lee Shapiro, MD

# DVD LIBRARY

- 272 **10/25/15** – RUTGERS EDUCATION FORUM; New Brunswick, NJ - Understanding & Managing Incontinence, Juana Hutchinson-Colas, MD  
Living Well with Chronic Pain, Casey Cashman
- 273 **11/14/15** – HSS RESEARCH FORUM; NY, NY - Drug Development & Scleroderma, Richard M. Silver, MD  
Biomarkers in Systemic Sclerosis; From Skin to Lungs, Romy Christmann, MD, PhD
- 274 **4/24/2016** – HSS EDUCATION FORUM - Stem Cell Therapy for Scleroderma, Richard K. Burt, MD
- 275 **5/15/2016** – EDUCATION FORUM; Stony Brook – PAH & Scleroderma, Paul Strachan, MD | Raynaud's Phenomenon, Howard Blumstein, MD
- 276 **8/2016** – Carol Artlett, PhD Identifying A New Target for the Treatment of Fibrosis
- 277 **9/2016** – ALBANY PT. ED FORUM - Calcinosis & Scleroderma, Mitchell Miller, PharmD Candidate | Proton Pump Inhibitors; How to Digest the News, Jessica Farrell, PharmD | Leadership and the Four Phases of Chronic Illness, Patricia Fennell, MSW, LCSWR
- 278 **9/2016** – YALE PT. ED FORUM - Living with Scleroderma; Dealing with the Impact of Illness on Your Personal Life, Lenore Buckley, MD, MP  
Managing Raynaud's Phenomenon, Oana Zaha, MD | Pulmonary Hypertension in Scleroderma, Wassim Fares, MD
- 279 **10/2016** – ROCHESTER PT. EDUCATION FORUM - Scleroderma; What You Need To Know, Janet Pope, MD  
Coping with Chronic Illness & Panel Discussion, Christine Jean-Jacques, PhD
- 280 **10/2016** – PT. EDUCATION FORUM; Mt. Sinai/Beth Israel - Hand Surgical Options, Charles Melone, MD | Scleroderma & PAH, Roxana Sulica, MD  
Scleroderma Overview, Erin Patton, MD
- 281 **10/2016** – KGS2! DISC 1: Don't Sit on Your Cactus , Chanel White - Keynote Speaker | How We Treat Common Problems in Scleroderma, Anne Stevens, MD  
and Suzanne Li, MD, PhD | What Do We Think Causes Scleroderma, Anne Stevens & Kathryn Torok, MD " | DISC 2: What's Happening in Juvenile  
Scleroderma Research, Dr. Li and Theresa Lu, MD, PhD | Is There a Best Diet for Scleroderma, Lynda Rosini, MA, RDN, CNSC, CDE | School Days-  
Managing Scleroderma Issues, Doreen Tabussi, MSN, APN, CPN
- 282 **10/2016** – JOINT PT. ED FORUM - Scleroderma Dental Issues, Vanlentina Lyssova, DDS | Scleroderma Research Efforts and the Importance  
of Patient Participation, Vivien Hsu, MD
- 283 **11/2016** – RESEARCH FORUM - Sjogren's Syndrome: Overview and Research Efforts, Alan Baer, MD | What is Autoimmunity and Current Research  
Alessandra Pernis, MD
- 284 **04/2017** – PATIENT EDUCATION FORUM AT HSS - Musculoskeletal Manifestation of Systemic Sclerosis, Jessica Gordon, MD | Scleroderma: From the Bench  
to the Clinic , Carol Feghali-Bostwick, PhD
- 285 **08/2017** – DAEMEN COLLEGE PATIENT ED FORUM – Mary Margaret O'Neil, MD, "Scleroderma Diagnosis & Treatment Options" and  
Jennifer Frustino, DDS, PhD "Scleroderma Oral Health"
- 286 **09/2017** – ALBANY PATIENT ED FORUM - Aixa Toledo-Garcia, MD "Scleroderma Overview", Vivek R. Mehta, MBBS "Life After 20 Years of Scleroderma"  
DISC 2: "Aixa Toledo-Garcia, MD "Esclerodermia O Esclerosis Sistematica"
- 287 **09/2017** – UCONN HEALTH PATIENT ED FORUM – Santhanam Lakshminarayanan, MD, "Coping With Daily Issues in Scleroderma"
- 288 **10/2017** – ROCHESTER PT. EDUCATION FORUM – Katie Orem, MPH "Advanced Care Planning, Palliative Care & MOLST", Katie Adamides, Esq. "Power of Attorney  
and Wills", R. James White, MD, PhD "Scleroderma and Lung Involvement"
- 289 **10/2017** – RUTGERS PT. EDUCATION FORUM – Fabian Mendoza, MD "Scleroderma Vasculopathy"; Fabian Mendoza, MD "Que es Esclerodermia"  
y "Vasculopatia' en Esclerodermia"
- 290 **11/2017** – HSS PT. ED. FORUM - Robert J. Kaner, MD "Scleroderma Interstitial Lung Disease and Emerging Therapies" and Theresa Lu, MD, PhD, Improving  
Adipose-Derived Stem Cell Therapy in Scleroderma"
- 291 **12/2017** – Margrit Wiesendanger, MD, PhD "Scleroderma Symptoms and Management", Ioannis Tassioulas, MD, PhD "Pathogenesis and Treatment Approaches",  
Maria Padilla, MD "Pulmonary Manifestations of Scleroderma" – SPANISH: Margrit Wiesendanger, MD, PhD "Esclerodermia- "Sintomas y Tratamiento",  
Maria Padilla, MD, PhD "Manifestaciones Pulmonar de Esclerodermia"
- 292 **05/2018** – COLUMBIA/NY PRESBYTERIAN ED FORUM – Elana Bernstein, MD, MSc "Stem Cell Transplantation in Systemic Sclerosis"; Daniela Jodorkovsky  
"GI Dysmotility in Scleroderma – Not Just the Esophagus; Stephanie Gallatano, MD "Skin Deep-Dermatologic Management in Scleroderma"
- 293 **09/2018** – LONG ISLAND ED FORUM – Sonali Narain, MD, MPH "Musculoskeletal Symptoms in Scleroderma"; Jonathan Bank, MD "Fat Grafting for Scleroderma  
and Raynaud's; Arunabh Talwar, MD "Lung Involvement in Scleroderma"

## DVD LIBRARY

- 294 **09/2018** – ALBANY ED FORUM – Celeste Freeman, OTR/L, CHT “Scleroderma and Raynaud’s, Ideas for Managing Your Daily Routines”; Michelle Morgan, MS, RDN “Healthy Eating with Scleroderma; Shohreh Anand, EdD “How Scleroderma Patients Managed Their Illness: A Study Report”
- 295 **10/2018** – Rochester Ed Forum – Christopher Palma, MD “Breathlessness in Scleroderma: Causes, Tests and Solutions”; Nana Duffy, MD “Cutaneous Manifestations of Systemic Sclerosis; Theo Munson, MPH “Dealing with Loss and Trauma”
- 296 **11/2018** – HSS RESEARCH FORUM – Jonathan Garlick, DDS, PhD “Building Human Skin to Study Scleroderma”; Jessica Gordon, MD “Participating in Clinical Trials”; John Varga, MD “The Scleroderma Foundation Research Grant Program. Finding the Cause and Cure for Scleroderma.

## ADDITIONAL RESOURCES

- 300 ASSISTED YOGA FOR SCLERODERMA, with Kathy Randolph
- 301 PROJECT SCLERODERMA: Beneath the Surface, Narrated by Bob Saget; Executive Director, Christy McCaffrey
- 302 SCLERODERMA; THE TRUTH, a documentary by Dr. Ginny Orzel, SUNY Brockport
- 303 2015 NATIONAL PATIENT CONFERENCE VIDEOS – Multi-Disc Set
- 304 2016 NATIONAL PATIENT CONFERENCE VIDEOS – Multi-Disc Set
- 305 2017 NATIONAL PATIENT CONFERENCE VIDEOS – Multi-Disc Set