

New Hampshire Family Voices
Lending Library

Books on Genetic Conditions



09/2008

NH Family Voices
Tel: 1-800-852-3345 X 4525
Or (603) 271-4525
www.nhfv.org

New Hampshire Family Voices has available the following books in the lending library. Children's books are marked with a ♥.

Books are sent through the mail with a postage paid return envelope.

Evans, Ashleigh & Evans, Alice

♥**ANGEL LADY**

Sea View Publishing, 1995

Mother and daughter co-author this book to give a positive family view of Angelman Syndrome. Light and enjoyable reading.

Evans, Alice & Hyman, Julie

ANGELMAN SYNDROME FROM A-Z - EVERYTHING YOU EVER WANTED TO KNOW ABOUT ANGELMAN AND THEN SOME

Angelman Syndrome Foundation

Information and tips contributed by families and parents of children with Angelman Syndrome.

Zeis, Joanne

YOU ARE NOT ALONE: 15 PEOPLE WITH BEHCET'S

Self Published, 1997

Information about the diagnosis of Behcet's Disease and writings by fifteen people ranging from age 8 years to adult. Treatment suggestions are included.

Wagman, Rachael B.; Kantanie, Sharon L. & Kaplan, Fredrick S., MD

WHAT IS FOP? FIBRODYSPLASIA OSSIFICANS PROGRESSIVA: A GUIDEBOOK FOR FAMILIES

International FOP Association, 1995

This guidebook answers questions that families may have about FOP. Also includes more in depth articles on certain subjects of interest to families, such as surgery.

Stenson, Carol M. PhD; Daley, Steven E. PhD; Holladay, Kris & Farmer, Patricia A. EDS

WOLF-HIRSCHHORN SYNDROME (DELETION 4P): A GUIDEBOOK FOR FAMILIES

University of Nebraska / Munroe Meyer Institute, 1999

This guidebook provides an overview of the syndrome, and tips for families. Includes many quotes from families.

♥We have many other books in the NH Family Voices lending library which you may find of interest, including those on parenting children with special health care needs, managing educational issues, behavior, toilet teaching, and hospitalization.

Call us if you are looking for materials or information. We will be happy to assist you.

1-800-852-3345 ext 4525 (toll free in state) or
(603) 271-4525

A GUIDE TO TURNER'S SYNDROME (video)

Turner's Syndrome Society

Baker—Gomez, Sherry

MISSING GENETIC PIECES: STRATEGIES FOR LIVING WITH VCFS: THE CHROMOSOME 22q11 DELETION

Desert Pearl Publishing, 2004

Written by a parent, whose child is now 25, who was not diagnosed until the age of 18. This very thorough guide is a result of her quest for information, and provides info on identifying symptoms, as well as tips, education, advocacy.

Cutler-Landsman, Donna

EDUCATING CHILDREN WITH VELO-CARDIO-FACIAL SYNDROME

Plural Publishing Inc, 2007

Part One is a thorough overview of the syndrome from a medical and educational standpoint. Part Two focuses on interventions, tips and strategies for children at each age of development.

Sforza, Teri

THE STRANGEST SONG: ONE FATHER'S QUEST TO HELP HIS DAUGHTER FIND HER VOICE: THE COMPELLING STORY OF THE LINK BETWEEN A RARE GENETIC DISORDER AND MUSICAL TALENT

Prometheus Books, 2006

The inspiring story of Gloria Renhoff, who has Williams Syndrome, and her amazing musical ability. Despite not being able to read music or write her name, she is a classically trained soprano, and can sing hundreds of songs, in many languages.

Richard, Gail J. & Hoge, Debra Reichert

THE SOURCE FOR SYNDROMES 1

LinguiSystems, Inc., 1999

This publication gives a global understanding of the primary diagnosis with focus on the pertinent speech and language characteristics that can assist with generating goals and strategies to begin intervention efforts, directed at a pre-school level.

Syndromes covered in this volume : Angelman, Asperger's, Autism, Down Syndrome, FAS, Fetal Rubella, Fragile X, Landau-Kleffner, Prader-Willi, Rett's, Selective Mutism, Tourette's, Williams

Richard, Gail J. & Hoge, Debra Reichert

THE SOURCE FOR SYNDROMES 2

LinguiSystems, Inc., 2000

In this second publication, the authors again provide an overview of specific syndromes, and provide characteristics which may assist with generating goals and strategies for interventions, particularly geared toward the pre-school level.

Syndromes covered in this volume: Apert, Beckwith-Wiedemann, CHARGE, Cri-du-Chat, Crouzon, Goldenhar, Klinefelter, Moebius, Mucopolysaccharidoses, Noonan, Pierre-Robin, Stickler, Sturge-Weber, Treacher Collins, Usher, Velocardio-facial Syndromes, Waardenburg

Griffin, Elizabeth

FRAGILE X FRAGILE HOPE: FINDING JOY IN PARENTING A CHILD WITH SPECIAL NEEDS

Emerald Books, 2005

Written by a Mom whose son has autism and Fragile X, this story chronicles her journey through grief and depression, to acceptance and joy. She includes many helpful tips on toilet training, discipline, and encouraging a child to eat well.

Busby, Mary Beth & Massey, Megan

DEAR MEGAN: LETTERS ON LIFE, LOVE AND FRAGILE X: A GIFT FOR ALL PARENTS OF DISABLED CHILDREN

Capital Books, 2006

Written as a series of letters between two mothers, each with two children with Fragile X syndrome. This is an intimate look into both the joys and the challenges of parenting, and supporting one another.

Dunsford, Clare

SPELLING LOVE WITH AN X: A MOTHER, A SON, AND THE GENE THAT BINDS THEM

Beacon Press, 2007

The writer's adult son was diagnosed with Fragile X at the age of 7. Beautifully written, very honest, intimate story reflects her feelings, thoughts from birth, through diagnosis, to his becoming an adult. It is truly a story of love and adventure.

MITOCHONDRIAL AND METABOLIC DISORDERS - A PRIMARY CARE PHYSICIAN'S GUIDE

Psy-Ed Corp., Exceptional Parent Magazine, 1997

A monograph of articles pertaining to the spectrum of Mitochondrial disease, diagnosis, treatment and research.

MITOCHONDRIAL AND METABOLIC DISORDERS - A PARENT'S GUIDE

Exceptional Parent Magazine, 1998

A monograph of articles pertaining to the spectrum of Mitochondrial and metabolic diseases, family stories, therapies, and resources.

♥Duno, Patricia J.; During, Ann M.; Jeffers, Janet M.

PRADER-WILLI AND YOU: FEELINGS, DIETS, ACTIVITIES

Prader-Willi Syndrome Association, 1991

Written for children, this book talks directly about the things that are difficult for them (some behavior, weight management, learning challenges), and feelings about them. Provides some tips on diet and activity.

Children's Hospital - Oakland, CA Sickle Cell Center

A PARENT'S HANDBOOK FOR SICKLE CELL DISEASE (BIRTH TO SIX YEARS)

State of CA Department of Health Services, Genetics, 1990

Information about the progression of Sickle Cell as well as treatment options and daily care issues.

Anderson, Rebecca Rae, MS & JD & Buehler, Bruce A. MD

SOTOS SYNDROME - A HANDBOOK FOR FAMILIES

Munroe-Meyer Institute, 1992, 2000

This handbook covers many aspects of Sotos Syndrome. Glossary included.

Stenson, Carol M. PhD; Daley, Steven E. PhD & Farmer,

Patricia, Ed.S.

TRISOMY 13: A GUIDEBOOK FOR FAMILIES

University of Nebraska/Munroe Meyer Institute, 1999

This guidebook addresses the diagnosis of Trisomy 13 along with family tips.

Stenson, Carol M. PhD; Daley, Steven E. PhD; Holladay, Kris &

Farmer, Patricia A. Ed.S.

TRISOMY 18: A GUIDEBOOK FOR FAMILIES

University of Nebraska / Munroe Meyer Institute, 1999

This guidebook addresses the diagnosis of Trisomy 18, as well as provides family tips.

Rieser, Patricia, RN & Underwood, Louis, MD

TURNER SYNDROME: A GUIDE FOR FAMILIES

Turner Syndrome Society, 1992

This book provides an overview of Turner Syndrome, from physical characteristics to medical, social and emotional issues which sometimes accompany this syndrome.

- We also have this material in Spanish: ***SINDROME DE TURNER***

Zarr, Loraine & Wiegrefe, Karla
FOR THE LOVE OF CHRISTIE

Prader-Willi Association, 1996

Written by a mother about her daughter's 26 year struggle with Prader-Willi, developed after treatment for a brain tumor.

Hunter, Kathy

THE RETT SYNDROME HANDBOOK

International Rett Syndrome Association, 1999

A comprehensive book that covers many aspects of Rett's.

Zimmermann, Susan

KEEPING KATHERINE: A MOTHER'S JOURNEY OF ACCEPTANCE

Three Rivers Press, 2004

Katherine was a typical baby for her first year of life. What followed that year is chronicled in a very personal, inspirational story of one family's journey from diagnosis with Rett Syndrome to changes the family faces over time.

Lindberg, Barbro

UNDERSTANDING RETT SYNDROME: A PRACTICAL GUIDE FOR PARENTS, TEACHERS, THERAPISTS

Hogrefe & Huber Publishers, 2006

The updated edition describes the difficulties, challenges faced by girls and women with Rett Syndrome, as well as proposed solutions.

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 an easy to read format, this contains a wealth of information on living a full & rich life while managing the condition.

♥Heinemann, Janalee

SOMETIMES I'M MAD, SOMETIMES I'M GLAD... ON BEING A PRADER-WILLI FAMILY

Prader-Willi Syndrome Association, 1982

Sarah, who is 7, talks about her brother Matt, who is 8, and has Prader-Willi Syndrome. This is a wonderful story which openly discusses how Prader-Willi Syndrome affects Matt, and the entire family.

♥Sexton, Valerie Rush & Fortin, Debbie Erbe

MICHAEL AND MARIE: CHILDREN WITH PRADER-WILLI SYNDROME

Prader-Willi Syndrome Association, 2003

A story of two children with Prader-Willi Syndrome (Michael, 10 & Marie, 6) as they move through the school day. While talking about physical and occupational therapy, eating and social issues, this story highlights that they are much like their classmates.

Ceppos, Suzanne Wise

PRADER-WILLI SYNDROME: A HANDBOOK FOR PARENTS (REVISED EDITION)

Prader-Willi Syndrome Association, 1999

Written by a parent, this is a thorough and encouraging guide. General information on Prader-Willi Syndrome, as well as tips on infant care, weight control, and health are included. Specific tips on mental, emotional, educational and social development also included.

THE EARLY YEARS - A COLLECTION OF ARTICLES REGARDING YOUNG CHILDREN WITH PRADER-WILLI

Prader-Willi Syndrome Association, 1998

This collection of articles and "ask the expert" responses is both informative and supportive, as it provides both general information and support from one parent to another.

Heinemann, Janalee

GROWING UP WITH PRADER-WILLI SYNDROME: THE PERSONAL REFLECTIONS OF A MOTHER

Prader-Willi Syndrome Association, 2003

A series of articles written over the course of years. The articles touch on her feelings, diet secrets, dealing with behavior issues, maintaining a healthy marriage, sibling issues, and her son's hopes and dreams for his future.

Wharton, R.H., MD; Levine, K., PhD; Fragala, M. PT; Patch, D.C.M., MS, CCC-SLP

THE CHILD WITH PRADER-WILLI SYNDROME: BIRTH TO THREE

Prader-Willi Syndrome Association, 1999

Provides an overview of the early years of life for a child. Tips for encouraging play & speech, addressing muscle tone, sleeping & eating issues. Parent story also included.

Levine, Karen, PhD; Wharton, Robert H., MD; Comeau, Margaret E.

CHILDREN WITH PRADER-WILLI SYNDROME: INFORMATION FOR SCHOOL STAFF (3RD EDITION)

Prader-Willi Perspectives, 1996

A great resource for parents and school personnel, this booklet provides basic descriptions of behavior and learning patterns, as well as strategies and tips.

Seguin, Julie A., MS, CRC & Hodapp, Robert M., PhD

TRANSITION FROM SCHOOL TO ADULT SERVICES IN PRADER-WILLI SYNDROME: WHAT PARENTS NEED TO KNOW

Prader-Willi Perspectives, 1998

Covers basic transition issues, from process, to differences between special education & adult services, to work and community living.

Unterberger, Donna

LOW-FAT, LOW-SUGAR RECIPES FOR THE PRADER-WILLI SYNDROME DIET (AND ANYONE ELSE WHO NEEDS TO WATCH CALORIES)

Prader-Willi Syndrome Association, 2003

157 pages of recipes. Includes baby food, snacks, cookies, breads, muffins, cakes, dressings, soups, salads, beverages, as well as main dishes. Also has recipes for play dough, blowing bubbles, face and finger paints.

Cox, Janice Hovasi, MS, RD; Doorlag, Denise, OTR

NUTRITIONAL CARE FOR INFANTS AND TODDLERS WITH PRADER-WILLI SYNDROME

Prader-Willi Syndrome Association, 1999

Answers some of the most commonly asked questions about nutrition and feeding of infants and toddlers with Prader-Willi Syndrome. Provides a lot of helpful pictures, food intake charts, sample menus and feeding recommendations.

Brogie, Karen H., M.A., R.D. (revised by Sherry Gray)

A NUTRITION GUIDE FOR PARENTS OF CHILDREN WITH PRADER-WILLI SYNDROME AGES 3-9 YEARS

Prader-Willi Syndrome Association, 2002

This booklet is designed to help parents meet the nutritional needs of young children with Prader-Willi Syndrome, and prevent overeating. Food exchange lists and tips for controlling access to food are included.

Borgie, Karen H., MA, RD (revised by Sherry Gray)

NUTRITION CARE FOR ADOLESCENTS AND ADULTS WITH PRADER-WILLI SYNDROME

Prader-Willi Syndrome Association, 2003

Written to help manage nutritional needs of adolescents and young adults who are living with Prader-Willi Syndrome. This book contains food exchange lists, as well as tips on eating out, and reading food labels.