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Prader-Willi Syndrome Assn QLD (Aust) Inc.

PO Box 8295, Woolloongabba, QLD 4102, Australia

Your name:	source	Please number in order of priority of interest
Address:		
ph no:		
email:		

BOOKS**Early Childhood****Our Babies**

24 pages. (2000). Parents of young children with PWS describe their feelings on having a baby diagnosed with PWS, and their feelings now. (Encouraging and positive)

UK

The Child with Prader-Willi Syndrome: Birth to Three

34 pages A5. (1999). The first part is written from a parent's view point, the second part by a paediatrician and other health professionals. It is intended to help parents as well as early intervention workers, physicians and care providers with advice on optimum care.

USA

Babies and Children with Prader-Willi Syndrome: a handbook for parents and carers

46 pages A4. (2001). An excellent book! Great layout, easy reading and with colour photo's. Covers about everything.

UK

Prader-Willi Syndrome and the Younger Child

24 pages A5 (1997 revised) A comprehensive introduction to PWS for "new" parents, family and care providers. Covers birth to about 12 years. Nicely written, practical and with photo's.

NZ

Directions: Help for parents of young children

38 pages A5 (1991). Written by parents and professionals. Basic information and offers guidance on many issues that arise in the years from birth to 5.

USA

The Early Years

42 pages A4. (1998). A collection of articles from "The Gathered View" regarding young children with PWS, includes stories told by parents.

USA

Nutritional Care for Infants and Toddlers with Prader-Willi Syndrome

62 pages A5 (2000). Discusses common early infant feeding problems, feeding aids, growth and nutrition for this age group. Answers to frequently asked questions.

USA

Nutrition Care for Children with Prader-Willi Syndrome: A nutrition guide for parents of children with PWS. Ages 3 to 9 years

12 pages A5. Covers calorie needs, supplements, diet planning and food management, and explains food exchange lists.

USA

Handbook for Parents (Revised in 1999)

Written by Shirley Neason in 1978, with subsequent revisions by members of the PWSA publications committee. A Comprehensive booklet, with pictures, that covers birth to adulthood. Parent-to-parent handbook for understanding and managing issues related to PWS. Softcover, 75 pages.

USA

My Ragdoll (New in 2001)

Written by Cheryl Couch from a Christian perspective. Cheryl shares her emotional roller coaster when her angel Elana is diagnosed with PWS. Softcover ; 229 pages

USA

Nutrition Care for Children with PWS, Infants and Toddlers (New in 2000)

Written by Janice Hovasi Cox, MS,RD and Denise Doorlag, OTR; consultants Dr. James and Carolyn Loker; edited by Linda Keder. Provides answers to frequently asked questions about nutrition and feeding of infants and toddlers with Prader-Willi syndrome(PWS). Softcover, 62 pages.

USA

Nutrition Care for Children with PWS, Ages 3-9 1994.

Written by Karen H. Borgie, M.A., R.D., for the Prader-Willi California Foundation. Covers calorie needs, supplements, diet planning and food management, and explains food exchange lists. Softcover, 12 pages.

USA

Physical Therapy Intervention for Individuals with Prader-Willi Syndrome

Written by Maria Fragala, PT; This booklet provides general information about physical therapy intervention. Softcover, 11 pages.

USA

Hello! I have PWS (4 page information sheet to be completed by person with PWS or parents for respite carers/teachers/youth leaders/child-minders etc.)

UK

Prader-Willi Syndrome: A handbook for parents and carers of babies and children with PWS. (ISBN 0 9521023 6 6) *By Jackie Waters*

UK

Prader-Willi Syndrome: Food and Health (ISBN 0 9521023 4 X) *by Margaret Gellatly (1996). (36 pages A5 paperback. How to provide a healthy diet for people with PWS, how many calories per day are required to maintain a healthy weight, with sample menus and weighed food lists giving calorie counted servings)*

UK

Home, School and Community (ISBN 0-412-45360-6) *by Terrance N James and Roy K Brown (1992). (223 pages paperback. Based on a study of families in Western Canada, looks at the major problems and offers practical suggestions for dealing with a range of issues concerning parents.)*

UK

Management of Prader-Willi Syndrome (2nd Edition) (ISBN 0-387-94373-0) edited by Louise R Greenswag and Randall C Alexander (1995). (393 pages, hardback. Each chapter written by a USA expert on PWS, including genetics, medical conditions, and dietary and behavioural management. A small part of the book is specific to the USA.)

UK

Prader-Willi Syndrome: A Practical Guide. Resource materials for teachers by Jackie Waters (ISBN 185346614X) (88 pages) *Practical help for teachers of 3-19yr olds with PWS. Cognition, abilities, and classroom management, with a medical overview.*

UK

NEW! Kenneth: Living with PWS (ISBN 0-473-05770-0) 134 page book about a man living in New Zealand. Recommended for professionals and parents of adults.	UK	
Our Way of Life (40+ pages in loose-leaf format. Information pack specifically for people with PWS, explaining the syndrome and how to manage it in pictures (many in colour) and words. Non-readers will need help. Suitable for those aged about 10 and over. Special additional section for over 14 year olds. Please state age and sex below when ordering the pack. Age..... Sex.....	UK	
Adolescence & Adults		
Prader-Willi Syndrome and the Older Person 27 pages A5 (2000 revised). Information on the adolescent and adult years.	NZ	
A Handbook for Parents and Carers of Adults with Prader-Willi Syndrome 44 pages A4. (1996). Covers behavior, medical, ethical and financial topics.	UK	
Beyond the Veneer: a guide to the essential features of residential care and supported living for adults with Prader-Willi Syndrome 20 pages A4. (1997) For parents and care providers.	UK	
Guidelines for the management of Prader-Willi Syndrome. 3rd edition A resource directed towards care-staff and other service providers working with adults with PWS. 44 pages A5 (1998)	AUS	
Transition From School to Adult Services in Prader-Willi Syndrome: What Parents Need to Know - Written by Julie A. Seguin, M.S., CRC, Robert M. Hodapp, Ph.D.; This booklet helps you understand what transition is, who provides services, and what you as a parent will need to do.	USA	
Behavior Management - A Collection of Articles (Revised in 2000) Compiled in 1998. This booklet includes general articles on behavior concerns, use of psychotropic medications, skin picking, and social skills teaching. Softcover booklet, 49 pages.	USA	
Parent's Guide to Alternative Living Arrangements - Written by Mildred Lacy. Provides guidance in evaluating residential options for adults with PWS. Softcover booklet, 13 pages.	USA	
Nutrition Care for Adolescents and Adults with PWS 1995. Written by Karen H. Borgie, M.A., R.D., for the Prader-Willi California Foundation. Covers essential diet information for families, caregivers, and residential service providers. Softcover, 24 pages.	USA	
Exercise and Crafts & Activities - A Collection of Articles (Compiled in 1998) Contributions by Jennifer C. Deau, M.S., Exercise Physiologist, and other articles on muscle tone, upper body strength, exercise, and crafts and activities for the individual with Prader-Willi syndrome from infancy to adulthood. Softcover booklet, 44 pages.	USA	
Nutrition for Adolescents and Adults with Prader-Willi Syndrome 24 pages A5 (1995). Covers essential diet information for families, caregivers, and residential service providers.	USA	
General		
My Grandchild has Prader-Willi Syndrome. Now what? 17 pages A5 (2000) Especially written for grandparents.	USA	
Prader-Willi Syndrome: home, school and community 193 pages. Includes parent stories and general information .	Canada	
Prader-Willi Syndrome 44 pages (in Dutch)	NL	
Growing up with Prader-Willi Syndrome: the personal reflections of a mother 38 pages A4 A collection of 15 articles from "The Gathered View".	USA	
Management of Prader-Willi Syndrome, Second Edition, Springer-Verlag 1995. Edited by Louise Greenswag, R.N., Ph.D., and Randell Alexander, M.D., Ph.D., of The University of Iowa. Latest edition of the only comprehensive textbook on PWS in print--each chapter is written by a specialist on that particular topic. Excellent reference tool. Softcover, 393 pages.	USA	
Planning for Their Future: General Estate and Guardianship Planning (1998) Compiled by attorneys for general information and guidance for families of persons with PWS. To be used in conjunction with counsel from legal and/or financial specialists. Softcover booklet, 30 pages.	USA	
Overview of the Prader-Willi Syndrome Revised 2000. Written by Lota Mitchell, M.S.W. Short introduction to the syndrome for professionals and parents. Covers both diagnosis and management strategies. Softcover, 13 pages.	USA	
Sometimes I'm Mad, Sometimes I'm Glad - A Sibling Booklet Written by Janalee Heinemann in the voice of a sibling of someone with PWS. Recognizes the range of feelings that arise in having a brother or sister with the syndrome.	USA	
Prader-Willi & You - For the person with the syndrome. Written by Patricia Duno, Ann During, and Janet Jeffers. A booklet for those with PWS who are having difficulty with diet and behaviour. The main character, Jamie, helps the reader understand that having PWS means having to learn special things about feelings, activities, and diet. Includes a food ticket system to control diet and tips on behaviour, exercise, and activities. Softcover, 30 pages.	USA	
For the Love of Christie - About Acquired PWS Book by Loraine Zarr about her daughter, Christie, who had "acquired" Prader-Willi syndrome. Christie was treated for a brain tumor and subsequently developed the classic symptoms of PWS. Moving story about the family's struggle with this outcome, leading up to Christie's death of obesity-related causes. Available exclusively through PWSA (USA). Softcover, 114 pages.	USA	

Nutrition - general

Food and Health

28 pages A5. (1996). Nutritional information and food lists by weight and caloric content.

UK

Prader-Willi Syndrome: practical ideas to help with weight control

42 pages A5. Very handy, great layout with lots of illustrations

UK

Wallet Cards for Restaurants Designed to be given out to restaurant wait staff (to ask that no extra food be offered) Pkg. 20 for \$2.00

USA

Wallet Cards for Legal Situations For law enforcement personnel (in case police ever become involved in a behaviour or food incident). Pk of 4 for \$1.00.

USA

Health and Medical Issues - A Collection of Articles. (Compiled in 2002)

A collection of articles for the individual with Prader-Willi syndrome. Softcover booklet, 121 pages.

USA

Health Care Guidelines for individuals with Prader-Willi syndrome (1998)

A brief overview of recommendations for birth - adulthood, written by Jeanne Hanchett, M.D. and Louise Greenswag, R.N., Ph.D., approved by PWSA-USA's Scientific Advisory Board. A resource for pediatricians, family practitioners, internists, geneticists, nurses, nutritionists, psychologists, allied health care providers, educators, and service agencies and as an aid to families/caregivers. Includes bibliography. Softcover, 20 pages.

USA

Nursing Management (Revised 1998)

Written by Geraldine M. DiCosimo, M.S., R.N., C.S. Guides nurses, school health personnel, and other health care practitioners through the major health issues that arise in the various stages of PWS. Softcover, 20 pages.

USA

Education

Prader-Willi Syndrome: a practical guide - Resource materials for teachers

85 pages A4. (1999) Very comprehensive. Covers classroom and behaviour management as well as educational techniques of three age groups: 1) preschool and primary, 2) secondary, and 3) further education.

UK

Information for School Staff Supporting the Student who has Prader-Willi Syndrome - across their Life Span

7 pages A4; Includes a cassette

USA

Educating the Child with Prader-Willi Syndrome

6 pages A4.

UK

Information for School Staff: Children With Prader-Willi Syndrome

Written by Robert H. Wharton, M.D., Karen Levine, Ph.D.; This booklet will assist teachers and other school personnel who have a child with Prader-Willi syndrome (PWS) in their class or school. Softcover, 23 pages.

USA

Audio Tape - Supporting the Student Who Has PWS - Across Their Life Span (1998) Professionally produced audio tape about PWS specifically designed for teachers. Includes a 27-minute audio tape, with an accompanying worksheet about PWS related issues and interventions for school staff, and the What Educators Should Know brochure.

USA

Transition to School: for young children with special learning needs

36 pages A4. (1997). Guidelines on what is involved in the transition process to primary in NSW. Written by the Education Department.

Behaviour & Health

Growth Hormone And Prader-Willi Syndrome: a reference for families and care providers.

53 pages A4. (2001). Excellent and comprehensible reading for those parents contemplating GH treatment for their children. With colour photo's of children before and on GH treatment. It is also a comprehensive reference for all medical providers considering using growth hormone with children who have Prader-Willi syndrome.

USA

Behaviour Management

79 pages A4. A collection of articles from "The Gathered View" on behaviour, medications, skin picking, toilet training and social skills teaching.

USA

Behaviour Management in Prader-Willi Syndrome

12 pages A4. (1999) Short overview.

UK

Health and Medical Issues: For the individual with PWS

95 pages A4. Information and collected articles from "The Gathered View".

USA

Vision and Care of the Eyes in Prader-Willi Syndrome.

4 pages A4.

UK

Conference abstract books

2001 International Prader-Willi Syndrome Scientific Conference. Minnesota, USA

2001 International Prader-Willi Syndrome General Conference. Minnesota, USA

2002 Australasian Prader-Willi Syndrome Conference. Sydney

2000 Australasian Prader-Willi Syndrome Conference. Melbourne

1998 International Prader-Willi Syndrome Conference: scientific. Lido di Jesolo, Italy

Scientific Books & articles

Mil, E.G.A.H. 2000 **Energy Metabolism in Paediatric Obesity**. Chapters 1-3 Introduction and energy expenditure in rest and when active in children and adolescents with PWS. Chapter 4 on body composition in PWS. 7 Chapters, 172 pages:

Gabriels B. 1998. **Vasopressin Secretion Disorders**. Chapters 4-5 are on PWS. 8 chapters, 167 pages

Prader Willi Syndrome in the New Millenium in The Endocrinologist Vol 10, no 4, Supp 1: 73 pages

To browse
in the library

Review and research papers on many other aspects of PWS:

- ◆ Growth Hormone Therapy Use in PWS: Virtually complete since 1995.
- ◆ Also large collection on use of growth hormone in adults and on growth hormone secretagogues.
- ◆ Behaviour, Psychology, Sleep, Vision, Speech, Dental, Diet, Metabolism, Exercise etc. Mainly since 1995.

To browse
in the library

Scientific Abstract 1998 International Scientific Workshop and Conference

USA

Scientific Abstract 1999 PWSA-USA Scientific Conference

Scientific Abstract 2000 PWSA-USA Scientific Conference

Video's

Video "Searching for Solutions" (16 minutes) Multipurpose video created by award winning producers and graphic artists.

USA

Extra / Inside Edition(approx. 15 minutes) Depicts food issues related to PWS of an elementary aged child.

USA

Leeza Show - "Food as an Ultimate Passion and Deadly Curse - Broadcast 5/26/98. Depicts a broad range of issues related to PWS. (Price is suggested donation to offset reproduction costs.)

USA

St. Louis News Special: "A Deadly Hunger" Five-part series on PWS. Features a family managing PWS at home and highlights the need for residential services for some students, for weight crisis intervention, and for adults with PWS.

USA

Staff Training Video - "Understanding Prader-Willi Syndrome" - A professionally produced video with good practical advise for individuals who work with persons who have PWS. The video is an 18-minute video designed to train service provider staff on the needs of individuals with PWS.

USA

International Conference 1998 - 2 Video Set - Amateur videos by Kumiko Egawa of Japan. Presentations by Drs. Cassidy, Ledbetter, Greenswag, and Hanchett, and Janalee and Al Heinemann from the US, as well as presenters from other countries.

USA

International Conference 2001 - "Opening Ceremony" Produced by Mark Ryan. A Tribute to PWS Children from Around the World. A Touching Tribute to Children with PWS - set to Music - 10 minutes

USA

Prader-Willi Syndrome – An Overview for Health Professionals (New in 2002) This outstanding medical overview video is a must for all health professionals who are not "experts" on Prader-Willi syndrome. It deals with all the major genetics and health care issues of the child with PWS.

USA

Prader-Willi Syndrome – The Early Years (New in 2002) This video offers help, and practical suggestions for those families with a young child newly diagnosed with PWS, Genetics, medical, early intervention, and family issues are presented, personalized with family interviews. Although focusing on young children, this video is a wonderful resource for schools and families with children of all ages.

USA

Keeping a Balance: an introduction to Prader-Willi Syndrome

32 minutes (1999) Interviews with experts on PWS and individual stories of 8 people with PWS.

UK

To be different is alright, too: Prader-Willi's Syndrome (English subtitles)

43 minutes (1996?) Shows the life of children and adolescents of different ages: from 2 to 29 year old. Parents express their feelings. Shows therapies used and a variety of schools attended. Adolescents and adults speak themselves about their life.

NL, Belgium

1999 Australasian PWS Conference, Melbourne. A/Prof Davies: Growth Hormone; Prof Swaab:hypothalamus;(Wayne:sexual development); Dr Rowell:drugs; Mr Radler:Behaviour

1999 Australasian PWS Conference, Melbourne. Davies & Thornton: Fighting fit; (Inge: Nutrition;) King: Teeth ; (Loughnan: Exercise;) Aharna: Chiropractic; My life with PWS

1999 Australasian PWS Conference, Melbourne. (Adams: Jesse Thompson: Music); ; Crawford: Art; Dowell: further education

2002 Australasian PWS Conference, Sydney. opening session (Puplick), keynote (Holland), workshops with Holland & Taylor

2002 Australasian PWS Conference, Sydney. Life style sessions (Kneipp, Apperley, Loughnan, Elson), PWS clinic roles & workshop

2002 Australasian PWS Conference, Sydney. Growth hormone (Dr Lee, Dr Scheermeyer); Sex hormone (Dr Steinbeck), Genetics (Dr Smith), care and sibling sessions (Hardwick, Sills & Robertson).

PRADER-WILLI SYNDROME: KEEPING A BALANCE (1999) 32 Mins. A UK produced overview of PWS, featuring the main characteristics of the syndrome, and sharing the experiences of families and people with PWS from babies through to adults.

UK

Brochures		
Helping with Diet Management - Children with Prader-Willi Syndrome at School.(New in 2000). A guide for parents and educators.	USA	
Late Teens and Young Adults Overview of issues faced when the child with PWS becomes an adult, including work, residential options, medical issues, finances, and guardianship.	USA	
Management of PWS in the Work Setting: A Guide for Employers and Supervisors Emphasizes careful supervision and consistency as keys to success; includes tips and strategies and a brief overview of the syndrome.	USA	
Medical Alert: A Diagnosis and Reference Guide for Physicians and Other Health Professionals Summary in chart form for medical personnel and other providers who need a quick introduction to PWS.	USA	
Medical Reference Guide: A Diagnosis and Reference Guide for Parents and Caregivers (new in 2001) Summary in chart form for parents who need a quick introduction to PWS.	USA	
My Child Has PWS-Now What? Support and information for families of newly diagnosed infants and children.	USA	
Prader-Willi Syndrome Weight & Behavior Management: Suggested Do's and Don'ts for controlling the two major problems associated with PWS.	USA	
PWSA (USA) General information about the syndrome and PWSA(USA). Designed for awareness and fund raising.	USA	
Questions and Answers on Prader-Willi Syndrome: Basic information about PWS for anyone unfamiliar with the syndrome.	USA	
Shelly has Prader-Willi Syndrome, where dieting is a lifetime struggle...and food is a killer For use where dramatic impact is needed, e.g., on legislators or decision-makers. Not recommended for parents of young children.	USA	
Someone You Know Has PWS Basic information for relatives, friends, neighbors, and others in contact with people with PWS.	USA	
Speech and Language and Prader-Willi Syndrome Summarizes speech problems associated with PWS and recommends ways to locate a speech-language pathologist to assist a child of any age.	USA	
What Educators Should Know About Prader-Willi Syndrome Offers guidelines and strategies for helping the student with PWS stay focused, develop skills and knowledge, and minimize problems associated with the syndrome in the school setting.	USA	
How to teach your baby to be physically superb.	Gymbaroo	
Boo1 - If only we had known – Laying the base for child development & learning by Margaret Sasse	Gymbaroo	
Tomorrow's children – takes a look at the basics of learning in the 21 st century. by Margaret Sasse	Gymbaroo	
B022 – SPMP GymbaROO forages 2 – preschool	Gymbaroo	
B021 – Perceptual-Motor Lesson Plans Leve1 – for ages 4-6 by Jack Capon	Gymbaroo	
B023 – Perceptual-Motor Lesson Plans Leve2 – for ages 5-7 by Jack Capon	Gymbaroo	
B002 - SuccessfulMovement challenges – Sequential specific activities	Gymbaroo	