

**Australian Chapter of the
BATTEN DISEASE SUPPORT AND RESEARCH ASSOCIATION
INCORPORATED**

ARBN 073 435 202, ABN 56 056 138 994
www.battens.org.au / Ph: (02) 43345785

Publication, DVD and Book Library – as at 3/10

These items can be borrowed by contacting Linda at info@battens.org.au

Publications:

1. ***Batten Disease: An Easy to Understand Guide*** - L W Johnston, et. Al.
This book is written in layman's language and covers Batten Disease, what it is, how it is diagnosed, how it is inherited, how it affects an individual, and about BDSRA – 50 pages.
2. ***Coping for Careproviders*** - Elise E. Labbe, Ph.D.
This book looks at the affects of Batten Disease on the family and how it can wear down the primary careproviders, i.e. Mum and Dad, and the importance of developing good coping skills – 25 pages.
3. ***Teach and Be taught; A Guide to Teaching Students with Batten Disease***
(rev 2002) - Wendy Bills, M.Ed., et. Al.
A practical information book for parents and teachers that addresses the issues of having a child with Batten Disease in school. Includes sections on Individualised Education Program (IEP), alternative communication, vision, social interactions, therapy, law, etc. – 60 pages.
4. ***Will You Walk With Us? – Batten Disease and Hospice Care*** ** L W Johnston, et. Al.
A book that is designed for Hospice workers to quickly give them an understanding of Batten Disease and what is happening including end stages, its affect on the family and that the parents are professionals – 20 pages.
5. ***Fundraising Ideas for Working Toward a Cure*** - L Houghtby & S Killebrew-Ross
A simple book that presents several ideas for fund-raising events. It is designed that when someone selects a fundraising event, someone from the BDSRA who has had a success with that event will help with the practical side of it and act as a guide. – 8 pages.
6. ***Handy Helpful Hints for Careproviders*** - Robert Wilhelm, et. Al.
A compilation of ideas from parents and other careproviders for caring for a child/ren with Batten Disease. – 12 pages
7. ***Batten Disease; Insights for Parents*** - L W Johnston, et. Al.
This book is a companion to "*Batten Disease; An Easy to Understand Guide.*" It is for parents of children with Batten Disease and deals with the questions and issues that parents want to know.
– 30 pages
8. ***Medications*** - Nancy Carney, RN – BDSRA RN Medical Liaison/Educator
A compilation of medication most commonly used by children with Batten Disease. Includes anticonvulsants, antispasmodics, antidepressants, sedation, drugs for other problems. – 139 pages
9. ***Respiratory System*** - ** Nancy Carney, RN – BDSRA RN Medical Liaison/Educator
A look at the respiratory system, what happens with Batten Disease and how to deal with some of the problems. – 82 pages

**Australian Chapter of the
BATTEN DISEASE SUPPORT AND RESEARCH ASSOCIATION INCORPORATED**

10. **Gastrointestinal System** - ** Nancy Carney, RN – BDSRA RN Medical Liaison/Educator
About the Gastrointestinal system, how it works from the lips through the end, how it is affected by Batten Disease.
Chapters on nutrition, feeding techniques, feeding devices and problem solving.
– 175 pages
11. **Pressure Sores** - ** Nancy Carney, RN – BDSRA RN Medical Liaison/Educator
What is a pressure sore, causes, how to prevent and how to treat. – 32 pages.
12. **Dental Issues & Mouth Care** - Nancy Carney, RN – BDSRA RN Medical Liaison/Educator
What to look for, causes and suggested procedures. – 62 pages
13. **Physical Therapy** - Nancy Carney, RN – BDSRA RN Medical Liaison/Educator
What is appropriate, causes and suggested practices. – 167 pages
14. **How to Organise Special Events & Festivals** - Rob Tonge, Tourism Management Series
A Practical guide for Non-Profit Clubs & Associations. – 63 pages
15. **Instructions for Hospitals and Emergency Room Visits** - Nancy Carney, RN – BDSRA RN Medical Liaison/Educator
16. **Dementia in Children, Teenagers and Young Adults** -
A guide for parents, teachers and care professionals. This book addresses the dementia issues that many families
experience, especially those who have children with JNCL. The book explains what can cause dementia,
symptoms, and different therapy interventions. - 29 pages
Nancy Carney, RN – BDSRA RN Medical Liaison/Educator
17. **Therapy and Teaching with Batten Disease** -
A data source based on survey research with Australian participants. Investigates similarities of care, strategies
used by parents, teachers and therapists. Compiled by BDSRA Australian Chapter
18. **The Bumpy Road of Battens** –
A beginner's guide to getting Programs and Services. Amy Lombardi, MSW, LSW – BDSRA USA Family
Services
- 25 pages.
19. **Transition to Adulthood Checklist** –
Amy Lombardi, – BDSRA USA Family Services
20. **Death & Dying: A Helpful guide in dealing with the many 'End of Life' Issues** –
Amy Lombardi, – BDSRA USA Family Services
21. **How to Help Siblings Cope: A resource guide for understanding how
siblings deal with grief and loss** –
Amy Lombardi, – BDSRA USA Family Services

Note: Most publications have been produced by the BDSRA in USA, therefore terminology and in some instances may be applicable to the United States only.

*** This indicates that this publication is more suitable to families with more advanced affected children.

**Australian Chapter of the
BATTEN DISEASE SUPPORT AND RESEARCH ASSOCIATION INCORPORATED**

DVDs:

1. **DVD: *Teach & Be Taught, Volume I – Communication*** Wendy Bills, M.Ed., et. Al.
A visual look at ideas to help parents and teachers with communication and sensory strategies in relation to children affected by Batten Disease.
Approx. run time of 30 minutes.
2. **DVD: *Teach & Be Taught, Volume II – Behavioural issues.*** Wendy Bills, M.Ed., et. Al.
A visual look at ideas to help parents and teachers with behavioural issues and strategies for children affected by Batten Disease.
Approx. run time of 30 minutes.
3. **DVD: *Teach & Be Taught, Volume III – Educating Children with Infantile or Late Infantile.*** Wendy Bills, M.Ed., et. Al.
This third volume is specifically for those schools and teachers educating students with Infantile and Late Infantile Batten Disease. It helps to address some of the challenges of a child who cannot speak for his/herself as well as ways to integrate more sensory directed learning techniques. This DVD is also great for students who are in the later stages of JNCL..
Approx. run time of 30 minutes.
4. **DVD: *'3 Journeys: Living with Batten Disease'*** The Australian Chapter
This film was produced by the Australian Chapter as a visual and awareness of Batten Disease through the lives of three children. It identifies the forms of Battens and their symptoms, physical changes and the affect on the family. Narrated by a Paediatric Neurologist and provides information about research and the BDSRA.
Approx. run time of 12 minutes.

Books:

1. ***Twin Stars*** - Katy Eschler, Sydney Australia
This is a personal story by a mother of twin children affected by Batten Disease. A moving story from their birth through each milestone, challenge and joy of their terminal life. Katy has published this book to share an insight to the emotions, triumphs and courage endured by their battle.
2. ***Play Helps*** - Roma Lear, Teacher and Home Tutor of Disabled children
A book of Toys and Activities for Children with Special Needs. – 186 pages
3. ***Facing the Crowd*** - Deborah Fullwood (Special Education) & Peter Cronin (Occupational Therapy)
A book of Managing other people's insensitivities to your disabled child – 111 pages
4. ***Daring to Live Life*** - By Alina Dalentoft
A story about a young man's last two years and how life despite his incurable and rare disease—Batten Disease—can become meaningful after all.
5. ***...Nothing Can Separate Us...*** By Connie Jackson
An autobiographical account of this mother's spiritual and emotional struggle with grieving the loss of three of her six children.
6. ***Eight To Hope*** - By Wendy Bills, Ph.D.
Based on factual events involving Batten Disease.

Please contact the Publications Librarian if you would like to borrow any of these items:
Linda McLachlan on 03 51992628 or email: info@battens.org.au