



Launching of the upcoming Textbook:

Juvenile Neuronal Ceroid Lipofuscinosis (JNCL) and Education

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Authors: Texts contributions from authors from twenty organisations and seven countries (England, Scotland, USA, Norway, Denmark, Finland and Germany) representing the educational sector, the health/medical sector, the university sector and national peer organisations.

Juvenile neuronal ceroid lipofuscinosis (JNCL) is characterized by severe visual impairment with onset around age 4–8 years, and a developmental course that includes blindness, epilepsy, speech problems, very very early dementia, motor coordination problems, and behavioral and emotional reactions. There is presently no cure and the disease leads to premature death. Most of their lifespan, education is the core activity for children and adolescents with JNCL and their peers, but there is little systematic knowledge about their education, positive and negative school experiences, and the transition to adulthood.

The chapters in the present volume describe the characteristics of children and adolescents with JNCL on the basis of prior research and a large survey and interview study, the development paths and the variation in perceptual, cognitive and language abilities through the course of the disease. The book presents and discusses the diverse forms of educational organization in relation to JNCL, the educational possibilities and challenges due to the visual impairments and the very very early onset of dementia, and the possibilities that exist for supporting the coping and learning of students with JNCL within and outside the classroom. The book presents adapted and special needs education strategies that may contribute significantly to improved learning conditions, better maintenance of skills, and less frustration for individuals with JNCL, both evidence based strategies and strategies that are still in an experimental stage. The book is mainly focusing on «the education age» but some of the chapters discuss transition to adulthood and a more varied adaptation of the physical and social environment.

Main Themes/Parts

The book consists of seven main themes / parts:

Part 1 discusses basic issues, including the biological bases of JNCL and the variation in consequences of reduced perceptual, motor, cognitive and language abilities.

Part 2 presents an overview of educational measures, perspectives on teaching and learning, organization of ordinary and special education, early intervention, and education plans for student with JNCL, as well as training and support for staff working with this group of students.

Part 3 discusses adapted and special education topics, including the teaching of reading and writing, communication and language, mobility, handicraft, music and drama, and the use of technology. It also includes some remarkable educational histories.

Part 4 is about the consequences of JNCL for social life and participation, vertical and horizontal relationships, interaction within and outside the classroom, and the development and maintenance of autonomy.

Part 5 discusses the role of education in the transition from student life to adult living, and presents some illustrative life histories.

Part 6 is concerned with the family situation, parent needs and supports, and being a brother or sister of a child with JNCL.

Part 7 discusses behavioural and emotional reactions to the changes that are taking place in body and mind, and to a difficult and confusing life situation.

All the chapters present prior research and practice, results from the joint international study, and suggestions for further development of educational and participatory strategies.

The book consists of 34 chapters

Content

Foreword

Background, target groups, acknowledgements and funding

Contributors

Introduction

A short historical overview of JNCL. Towards evidence-based practice. The data from the study. Overview of issues and chapters.

Chapters

Part 1 Basic issues

1 A development perspective on JNCL

The concept of development, learning and development, typical and atypical development, the model of Baltes and Baltes

2 Biological bases of JNCL

Genetics, brain mechanisms etc.

3 Consequences of perceptual development and loss

4 Consequences of motor development and loss

5 Dementia, very very early onset dementia and JNCL

Cognition and memory mechanisms in dementia and their relevance for JNCL

6 Communication and language development and attrition

Language acquisition and attrition; language and JNCL

Part 2 Educational overview

7. Perspectives on education and learning

Implicit and explicit teaching and learning, skill based and participation based learning, pivotal learning, the use of personal preferences and interests

8 The organization of education and counselling

Adapted and special education, segregation and inclusion, educational organization and JNCL, including results from survey and teaching and learning in school settings in Germany and other countries

9 Teaching and learning, in progression and regression.

Educating students with visual impairment and dementia, dementia interventions and their relevance for JNCL

10 Planning education, assessment and intervention for students with JNCL

The functions of educational assessment, the role of assessment in the education of students with JNCL. What shall be assessed, when, why and by whom, implementation and evaluation of education and intervention, habilitation plans, individual education plans, transitions etc?

11 Early intervention related to JNCL in preschool and school

Prevention, building capacity for later use, hastened learning, life flow

12 Staff competencies and staff guidance

13 Teamwork in special education for students with JNCL

Multidisciplinary collaboration, merging general and special education

Part 3 Special educational topics

14 School subjects in general and special education

Orientation & mobility, natural and social science etc.

15 Reading and writing

Black print versus tactile reading and writing, Moon and Braille, technical writing devices

16 Communication and language in education

Manual signs and communication aids as communicative supplements

17 Physical education and activities

18 Handicraft

19 Music education and music in education

20 Technology and education

Computer access, Sarepta etc.

21 Drama and education

22 Some remarkable educational histories



Part 4 Social development and participation

23 The social life of children and adolescents with JNCL

Social consequences of JNCL, vertical and horizontal relationships, social training

24 Student collaboration and interaction in the classroom

25 After school

Leisure, interests, sports and hobbies; play and games

26 Autonomy in development and regression

Part 5 From student life to adult living

27 Learning for life

Vocational education, adapted work life

28 Transition to adult living

Model of transition, later participation and activity

29 Life histories

Part 6 The family

30 Parent needs and supports

Family participation, counselling, parent education, grief and coping; parents as specialists and the importance of collaboration and of parent contributions.

31 Being brother or sister of a child with JNCL

Part 7 Reactions to changes in body and mind

32 Behavioural reactions

Behavioural reactions to a difficult life situation; destructive behaviour, self-injury, behaviour disorders

33 Emotion regulation and mood

Anxiety and depression; hallucinations; case illustrations of positive results

34 Wellbeing and quality of life

Appendices

A Methods and tools

B Resources (associations, home pages etcetera).

C Recommended literature

D Glossary

Bibliography

The book will be published in 2018.

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