

PSYCHOLOGY OF DUCHENNE: LEARNING AND BEHAVIOR MUSCLE AND BRAIN

Dr. J. Hendriksen PhD



Parent Project
Muscular
Dystrophy

JOIN THE FIGHT.
END DUCHENNE.

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- The **AVERAGE BOY/MAN** with DMD does not exist
- **EVERY BOY/MAN IS UNIQUE:** with his own strenghts and deficits
- **NON-MOTOR PROBLEMS** play an unexpected important role



ASSUMPTIONS



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**PART 1:
GROWING UP WITH DUCHENNE**

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Journal of Neuromuscular Diseases 2 (2015) 313–324
DOI 10.3233/JND-150071
IOS Press

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Research Report

Health-Related Quality of Life in Children with Duchenne Muscular Dystrophy: A Review

Yi Wei, Kathy Speechley and Craig Campbell*
Department of Pediatrics and Epidemiology and Biostatistics, Western University

Literature review of 12 health related quality of life instruments.

.. Of all the health related instruments only the PEDSQL neuromuscular and the PARS-III have been validated specifically in a pediatric DMD population

QOL

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PSYCHOSOCIAL ADJUSTMENT IN 322 BOYS AND MEN WITH DUCHENNE

Journal of Pediatric Psychology Advance Access published July 22, 2008

Psychosocial Adjustment in Males with Duchenne Muscular Dystrophy: Psychometric Properties and Clinical Utility of a Parent-report Questionnaire

PARS-III

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PLOS | CURRENTS
MUSCULAR DYSTROPHY

Prednisone and Deflazacort in Duchenne Muscular Dystrophy: Do They Play a Different Role in Child Behavior and Perceived Quality of Life?

June 17, 2016 · Muscular Dystrophy

Citation

Sienko S, Buckon C, Fowler E, Bagley A, Staudt L, Sison-Williamson M, Zebracki K,

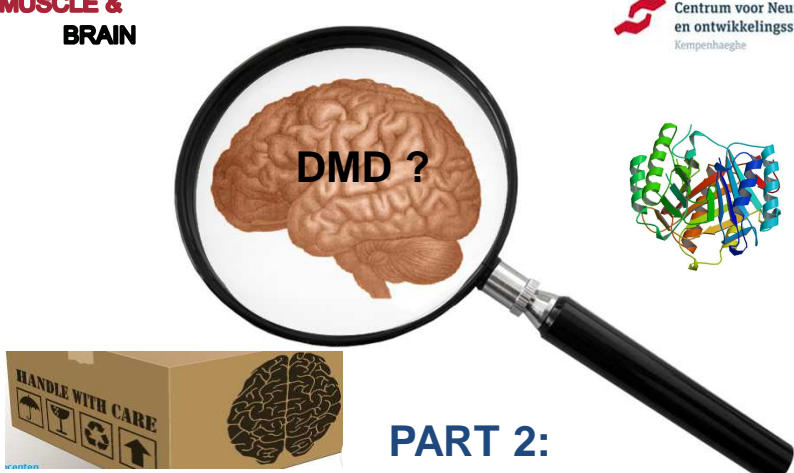
Hinton et al 2006,
Hendriksen et al 2008,
Buckon et al 2016

STEROIDS

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DMD ?

**PART 2:
BRAIN INVOLVEMENT:
COGNITION, LEARNING AND
BEHAVIOR**

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DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY ORIGINAL ARTICLE

Neurodevelopmental, emotional, and behavioural problems in Duchenne muscular dystrophy in relation to underlying dystrophin gene mutations

VALERIA RICOTTI¹ | WILLIAM P L MANDY² | MARIACRISTINA SCOTO¹ | MARIKA PANE³ | NICOLAS DECONINCK^{4,5} | SONIA MESSINA⁶ | EUGENIO MERCURI^{1,3} | DAVID H SKUSE² | FRANCESCO MUNTONI^{1,*}

Ricotti et al 2016: DYSTROPHIN ASSOCIATED NEURODEVELOPMENTAL DISORDERS:

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**DYSTROPHIN
ASSOCIATED
NEURO
DEVELOPMENTAL
DISORDERS**



**Obsessive
Compulsive
Disorder:**
DYSLEXIA
ASS: AUTISM SPECTRUM
DYSCALCULIA
ADHD: ATTENTION DEFICIT
DYSGRAFIA
MENTAL RETARDATION

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INTELLIGENCE

**Intelligence and
Duchenne muscular
dystrophy:
Full-Scale, Verbal, and
Performance
intelligence quotients**

Sue Cotton* BBSc (Hons) Grad Dip App Sc, Faculty of Health Sciences;
Nicholas J Voudouris PhD;
Kenneth M Greenwood PhD, School of Psychological Science, Faculty of Science, Technology and Engineering, La Trobe University, Victoria 3086, Australia.

Developmental Medicine & Child Neurology 2001, 43: 497-501 497

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SCHRANS & HENDRIKSEN
2012 review

INTELLIGENCE

**77 STUDIES (1954 – 2012);
N= 377 BOYS**

Wechsler Total IQ	88
Wechsler Performance IQ	93
Wechsler Verbal IQ	88


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READING PROBLEMS

DUCHENNE & DYSLEXIA: 27%
General population: 3%



**Are Males With Duchenne Muscular
Dystrophy at Risk for Reading Disabilities?**

Jos G.M. Hendriksen, PhD*¹ and Johan S.H. Vles, PhD, MD²

296 PEDIATRIC NEUROLOGY Vol. 34 No. 4

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doi:10.1016/j.pediatrneurol.2005.08.029 • 0887-8994/06/\$—see front matter

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ATTENTION DEFICIT


DUCHENNE & ADHD: 29%
General population 7%

EUROPEAN JOURNAL OF PAEDIATRIC NEUROLOGY 19 (2015) 521–524

 
Official Journal of the European Paediatric Neurology Society

Original article

Diagnostic overshadowing in a population of children with neurological disabilities: A cross sectional descriptive study on acquired ADHD

 CrossMark

J.G.M. Hendriksen ^{a,b,c,*}, J.C.A.W. Peijnenborgh ^{a,b,d}, A.P. Aldenkamp ^{b,c,d,e},
J.S.H. Vles ^{a,c,d}

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AUTISM

DUCHENNE & AUTISM : 5%
General population: 0,1%

Original Article

Neuropsychiatric Disorders in Males With Duchenne Muscular Dystrophy: Frequency Rate of Attention-Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder, and Obsessive–Compulsive Disorder

Joseph G. M. Hendriksen, PhD, and Johan S. H. Vles, MD, PhD

Journal of Child Neurology
Volume XX Number X
Month 200X
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http://online.sagepub.com

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STANDARD DIAGNOSTIC PROTOCOL

DIAGNOSTICS

AGE	0-6	6-10	10-15	>15
LEARNING	LANGUAGE IQ	ATTENTION READING MATH	SCHOOL PLANNING	
BEHAVIOR	AUTISM	ADHD OCD ANXIETY	IDENTITY SOCIAL	TRANSITION ACCEPTING DEPRESSION

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OVERVIEW:

TREATMENT OPTIONS

- Boys/men
 - Psycho education
 - Psychotherapy/behavior therapy
 - Cognitive training
 - Psychopharmaca
- Parents
 - Psycho education
 - Parent training
- School/therap
 - Psycho education
 - Behavior therapy

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PSYCHO-EDUCATION





The psychology of Duchenne Muscular Dystrophy
 Jos Hendriksen, Ruben Hendriksen, Justus Kuijjer and Elizabeth Vroom



www.parentprojectmd.org

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PSYCHOPHARMACA

Available online at www.sciencedirect.com

ScienceDirect

Neuromuscular Disorders 26 (2016) 659–661



www.elsevier.com/locate/nmd

Case report

Diagnosis and treatment of obsessive compulsive behavior in a boy with Duchenne muscular dystrophy and autism spectrum disorder: A case report

Jos G.M. Hendriksen ^{a,b,*}, Sylvia Klinkenberg ^{a,b}, Phillippe Collin ^{a,c}, Brenda Wong ^d, Erik H. Niks ^e, Johan S. Vles ^{a,b}

Report on a clinical significant and positive effect of Fluoxetine on OCD behavior.

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Thank you very much
for your attention



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