Summary for patients and parents

In September 2017 we obtained a grant for 4 years to develop and start a research project named “Follow You: an interprofessional follow up program and an individual intervention program for children and adolescents diagnosed with a connective tissue disorder” During this research project we want to unravel the cause of limitations in activities and participation in daily life. There after we hope to develop personalized interventions based on the causes to treat these limitations. We learned a lot regarding children and adolescents with Ehlers Danlos syndrome and have performed research regarding the clinical characteristics of them classified according to the ICF (see presentation J.Warnink). Since Marfan syndrome, Ehlers Danlos syndrome and Osteogenesis Imperfecta have in common that they are all diseases of the collagen and although the clinical presentation may vary, many problems the children and their parents meet are almost the same, for example the generalized joint hypermobility, decreased muscle strength, decreased exercise capacity and fatigue, we want to explore these characteristics in children and their parents in detail. Therefore, we are very proud that a 4 years study has been financed. Enclosed are the most slides of my presentation.

Thank you for the invitation. It was a pleasure to speak at the MEN event 2017. If you have any questions or ideas please contact me anytime.

Best wishes,

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University of Applied Sciences, Faculty of Health, Amsterdam

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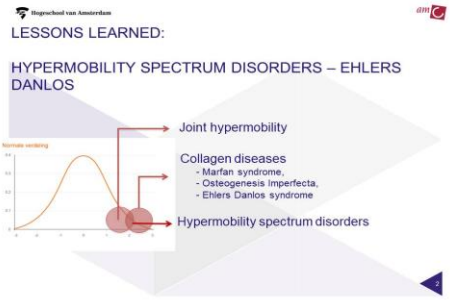

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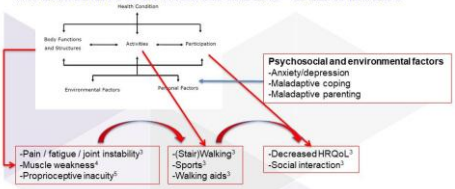
LESSONS LEARNED: HYPERMOBILITY SPECTRUM DISORDERS – EHLERS DANLOS



[3] Wolf JM et al. J Am Acad Orthop Surg. 2011 Aug;19(8):463-71.
[4] Rombaut L et al. Arthritis Care Res (Hoboken). 2012 Oct;64(10):1584-92.
[5] Sahin N et al. Rheumatol Int (2008) 28:995–1000

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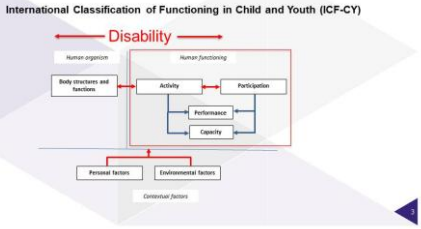
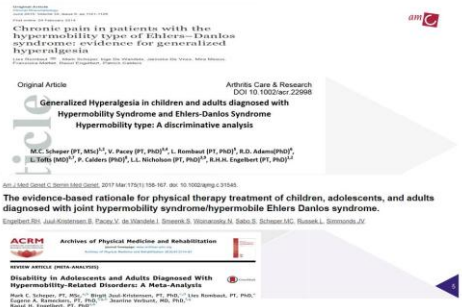
THEORETICAL FRAMEWORK OF DISABILITY





Original Article
Arthritis Care & Research
DOI 10.1002/acr.22998

Generalized Hyperalgesia in children and adults diagnosed with Hypermobility Syndrome and Ehlers-Danlos Syndrome Hypermobility type: A discriminative analysis

M.C. Scheper (PT, MSc)[1,2], V. Pacey (PT, PhD)[3,4], L. Rombaut (PT, PhD)[5], R.D. Adams(PhD)[6], L. Tofts (MD)[3,7], P. Calders (PhD)[8], L.L. Nicholson (PT, PhD)[3,9], R.H.H. Engelbert (PT, PhD)[1,2]

The evidence-based rationale for physical therapy treatment of children, adolescents, and adults diagnosed with joint hypermobility syndrome/hypermobile Ehlers Danlos syndrome.

Engelbert RH, Juul-Kristensen B, Pacey V, de Wandele I, Simeoni S, Wilmshurst N, Sabo S, Scheper MC, Russek L, Simmonds JV

Disability in Adolescents and Adults Diagnosed With Hypermobility-Related Disorders: A Meta-Analysis

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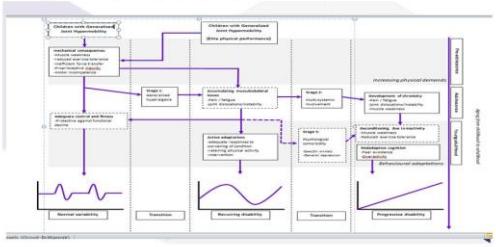
Rheumatology (Oxford). 2017 Apr 18. doi: 10.1093/rheumatology/kex148. [Epub ahead of print]

The natural history of children with joint hypermobility syndrome and Ehlers-Danlos hypermobility type: a longitudinal cohort study.

Scheper MC[1,2], Nicholson LL[3,4], Adams RD[5], Tofts L[3,6,7], Pacey V[8,9]



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FUNCTIONAL DISABILITY IN MARFAN SYNDROME IN CHILDHOOD /ADOLESCENCE

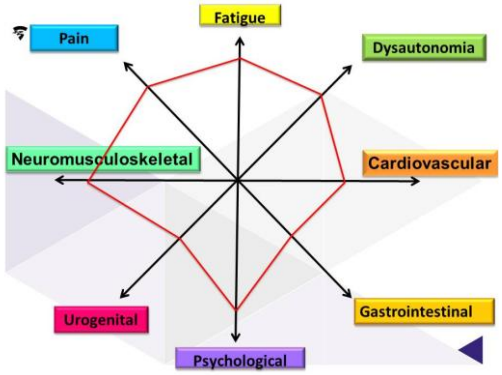
- What is known ?
- Few evidence; many questions in consulting room

"Is my child hypermobile ?"

"Fatigue is a huge problem: can she participate in sports ?"

"She is not able to write a letter ?"

"He feels depressed and is anxious during exercise?"



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SiA

FOLLOW YOU:

- Patient care and research
- Grant: 1000 K € (4 years follow-up)
- 200 children with Marfan and EDS Syndrome
- Amsterdam and Gent (B)

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SiA

FOLLOW YOU:

- Ethical approval
- In close collaboration with patients and patient societies
- Bi-Annual consultation besides regular visits to Marfan team
- Diagnostics / intervention / follow-up
- Patient care - research - education

FOLLOW YOU: QUESTIONS

- What do children and parents ask us ?
- What is normal in Marfan / EDS ?
- Do we understand why a child develops complaints?
- Can we help children and parents?

FOLLOW YOU: EXAMPLES

Pain measures

Fatigue and exercise tolerance measures

Questionnaires
- pain
- anxiety/depressoin
- self-confidence
- coping
- how do parents cope with this?
- functional ability

FOLLOW YOU

- Based on clinical reasoning, supported with evidence: what is the best interdisciplinary treatment for the child and the parents
- In strong collaboration with children
- Follow-up
- What can we learn of 200 children and their families over time?
- How can we share knowlegde with patients (societies), Marfan teams and professionals

FUTURE ASPECTS (1)

- Knowledge about natural course in Marfan and EDS syndrome
- Knowledge about why which child in what family develops complaints
- Understand and explain the complaints
- The effect of interventions (interdisciplinary)

FUTURE ASPECTS (2)

- Dissemination of knowledge
- International collaboration

Hogeschool van Amsterdam
Amsterdam University of Applied Sciences

VED Vereniging van Ehlers-Danlos patiënten

de Fysiotherapeut

de oefentherapeut CESAR MENSENDIECK

UNIVERSITEIT GENT

ergotherapienederland

UZ Universitair Ziekenhuis Gent

Nederlandse Vereniging voor Kinderfysiotherapie

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