

Overview publications and output 2021

Doctoral Degrees

- 18 jan 2021** Rijksuniversiteit Groningen
Promovendus: **I. (Ingrid) Kouwijzer**
HandbikeBattle: a challenging handcycling event.
Promotoren: Prof. dr. L.H.V. van der Woude
Prof. dr. M.W.M. Post
Copromotor: Dr. L.J.M. Valent
- 20 jan 2021** Rijksuniversiteit Groningen
Promovendus: **A. (Astri) Ferdiana**
Quality of life, work and social participation among individuals with spinal cord injury.
Promotoren: Prof. dr. U. Bültmann
Prof. dr. J.J.L. van der Klink
Prof. dr. M.W.M. Post
- 23 maart 2021** Universiteit Utrecht
Promovendus: **E.C.C. (Eline) van Lieshout**
Neurorehabilitation for upper limb recovery after stroke; the use of non-invasive brain stimulation.
Promotoren: Prof. dr. R.M. (Rick) Dijkhuizen
Prof. dr. J.M.A. Visser-Meily
Copromotor: Dr. H.B. van der Worp
- 7 juli 2021** Universiteit Utrecht
Promovendus: **M.E. (Marleen) Sol**
Wheelchair Mobility Skills in youth using a manual wheelchair. From Test to Training
Promotor: **Prof. dr. J.M.A. Visser-Meily**
Copromotoren: Dr. J.E. de Groot
Dr. O.W. Verschuren
- 23 sept 2021** University of Lucerne
Promovendus: **M. (Mayra) Galvis-Aparicio.**
Psychological Adaptation Following Spinal Cord Injury: An Exploration of the Clinical Rehabilitation Context.
Promotoren: Prof. dr. A. Gemperli
Prof. dr. M.W.M. Post
- 18 nov 2021** Universiteit Utrecht
Promovendus: **E.T. (Esther) Kruitwagen-van Reenen**
Health-related quality of life and participation of adult patients with spinal muscular atrophy and patients with amyotrophic lateral sclerosis.
Promotoren: **Prof. dr. J.M.A. Visser-Meily**
Prof. dr. L.H. van den Berg
Prof.dr. M.W.M. Post
- 30 nov 2021** Universiteit Utrecht
Promovendus: **J. A. (Joris) de Graaf**
Participation after stroke: towards personalized care
Promotoren: **Prof. dr. J.M.A. Visser-Meily**
Prof.dr. M.W.M. Post
Copromotor: **Dr. V.P.M. Schepers**

7 dec 2021 Universiteit Utrecht
Promovendus: **I.J.M. (Ilona) de Rooij**
Walking in relation to participation after stroke: Is virtual reality training of added value?
Promotoren: **Prof. dr. J.M.A. Visser-Meily**
Copromotor: Dr. I.G.L. van de Port
Dr. J.W.G. Meijer

22 dec 2021 Universiteit van Amsterdam
Promovendus: M. (Marijke) van Bloemendaal
Gait training and assessment in rehabilitation after stroke.
Promotoren: Prof. dr. F. Nollet
Prof. dr. A.C.H. Geurts
Copromotor: **Dr. J.A.J.M Beelen**
Dr. S.A. Bus

Scientific publications

1. Aben HP, De Munter L, Reijmer YD, Spikman JM, **Visser-Meily JMA**, Biessels GJ, De Kort PLM; PROCRAAS Study Group. Prediction of Cognitive Recovery After Stroke: The Value of Diffusion-Weighted Imaging-Based Measures of Brain Connectivity. *Stroke*. 2021 Jun;52(6):1983-1992
2. Adegeest CY, Van Gent JAN, **Stolwijk-Swüste JM**, **Post MWM**, Vandertop WP, Öner FC, Peul WC, Wengel PVT. Influence of severity and level of injury on the occurrence of complications during the subacute and chronic stage of traumatic spinal cord injury: a systematic review. *J Neurosurg Spine*. 2021 Nov 12:1-21. doi: 10.3171/2021.7.SPINE21537. Online ahead of print.
3. Anaby D, Ryan M, Palisano RJ, Levin MF, **Gorter JW**, Avery L, Cormier I, Teplicky R, Coulter J, Hanes J. Participation during a Pandemic: Forging New Pathways. *Phys Occup Ther Pediatr*. 2021;41(2):115-119. doi: 10.1080/01942638.2021.1875739.
4. Bailey K, Lee S, de Los Reyes T, Lo L, **Gorter JW**, Toulany A. Quality indicators for transition from paediatric to adult care for adolescents with chronic physical and mental illness: protocol for a systematic review. *BMJ Open*. 2021 Nov 1;11(11):e055194. doi: 10.1136/bmjopen-2021-055194.
5. **Bakers JNE**, De Jongh AD, Bunte TM, Kendall L, Han SS, Epstein N, Lavrov A, **Beelen A**, **Visser-Meily JMA**, Van den Berg LH, Van Eijk RPA. Using the ALSFRS-R in multicentre clinical trials for amyotrophic lateral sclerosis: potential limitations in current standard operating procedures. *Amyotroph Lateral Scler Frontotemporal Degener*. 2021 Dec 24:1-8. doi: 10.1080/21678421.2021.2016838. Online ahead of print.
6. **Bakers JNE**, Van den Berg LH, Ajeks TG, Holleman MJ, Verhoeven J, **Beelen A**, **Visser-Meily JMA**, Van Eijk RPA. Portable fixed dynamometry: towards remote muscle strength measurements in patients with motor neuron disease. *J Neurol*. 2021 May;268(5):1738-1746. doi: 10.1007/s00415-020-10366-9.
7. **Bakers JNE**, Van Eijk RPA, Van den Berg LH, **Visser-Meily JMA**, **Beelen A**. Pattern of muscle strength improvement after IVIg therapy in Multifocal Motor Neuropathy. *Muscle Nerve*. 2021 May;63(5):678-682. doi: 10.1002/mus.27185. Epub 2021 Feb 9.
8. Bootsma JN, Turkstra LS, **Gorter JW**. Expression of propositional attitudes in conversation by adults with traumatic brain injury: A relevance theoretic approach. *Int J Lang Commun Disord*. 2021 Mar;56(2):346-359. doi: 10.1111/1460-6984.12608.

9. Brunton LK, McPhee PG, **Gorter JW**. Self-reported factors contributing to fatigue and its management in adolescents and adults with cerebral palsy. *Disabil Rehabil*. 2021 Apr;43(7):929-935. doi: 10.1080/09638288.2019.1647294.
10. Conroy E, Kennedy P, Heverin M, Leroi I, Mayberry E, **Beelen A**, Stavroulakis T, Van den Berg LH, McDermott CJ, Hardiman O, Galvin M. Informal Caregivers in Amyotrophic Lateral Sclerosis: A Multi-Centre, Exploratory Study of Burden and Difficulties. *Brain Sci*. 2021 Aug 20;11(8):1094. doi: 10.3390/brainsci11081094.
11. **De Graaf JA, Visser-Meily JM, Schepers VP**, Baars A, Kappelle LJ, **Passier PE**, Wermer MJ, De Wit DC, **Post MW**. Comparison between EQ-5D-5L and PROMIS-10 to evaluate health-related quality of life 3 months after stroke: a cross-sectional multicenter study. *Eur J Phys Rehabil Med*. 2021;57(3):337-346. doi: 10.23736/S1973-9087.21.06335-8. Free article.
12. **De Graaf JA**, Nijssen B, **Schepers VPM**, Van Heugten CM, **Post MWM, Visser-Meily JMA**. Which approach to measure cognitive functioning should be preferred when exploring the association between cognitive functioning and participation after stroke? *Neuropsychol Rehabil*. 2021; 31(8): 1207-1223. doi: 10.1080/09602011.2020.1769687.
13. **De Graaf JA**, Volkens EJ, **Schepers VPM, Visser-Meily JMA, Post MWM**. Validity of the Utrecht scale for evaluation of rehabilitation-participation restrictions scale in a hospital-based stroke population 3 months after stroke. *Top Stroke Rehabil*. 2021 Jul 27:1-11. doi: 10.1080/10749357.2021.1956047. Online ahead of print.
14. **De Rooij IJM**, Riemens MMR, Punt M, **Meijer JWJG, Visser-Meily JMA**, Van de Port IGL. To What Extent is Walking Ability Associated with Participation in People after Stroke? *J Stroke Cerebrovasc Dis*. 2021 Nov;30(11):106081
15. **De Rooij IJM**, Van de Port, Punt M, Abbink-van Moorsel PJM, Kortsmid M, Van Eijk RPA, **Visser-Meily JMA, Meijer JWJG**. Effect of Virtual Reality Gait Training on Participation in Survivors of Subacute Stroke: Randomized Controlled Trial. *Phys Ther*. 2021 May 4;101(5):pzab051. doi: 10.1093/ptj/pzab051.
16. Dijkshoorn ABC, van Stralen HE, Sloots M, Schagen SB, **Visser-Meily JMA, Schepers VPM**. Prevalence of cognitive impairment and change in patients with breast cancer: A systematic review of longitudinal studies. *Psychooncology*. 2021 May;30(5):635-648.
17. **Dontje ML, Kruitwagen-van Reenen E, Visser-Meily JMA, Beelen A**; Study Group ALS Home-monitoring and Coaching. Implementation and evaluation of an e-health innovation for personalized care for patients with amyotrophic lateral sclerosis (ALS): protocol for a participatory action research study. *Implement Sci Commun*. 2021 Feb 25;2(1):25. doi: 10.1186/s43058-021-00130-z.
18. Dorton MC, Lucci VM, de Groot S, Loughin TM, Cragg JJ, Kramer JK, **Post MWM**, Claydon VE. Evaluation of cardiovascular disease risk in individuals with chronic spinal cord injury. *Spinal Cord*. 2021 Jul;59(7):716-729. doi: 10.1038/s41393-020-00566-5.
19. Faber W, **Stolwijk-Swüste J**, Van Ginkel F, Nachtegaal J, Zoetendal E, Winkels R, Witteman B. Faecal Microbiota in Patients with Neurogenic Bowel Dysfunction and Spinal Cord Injury or Multiple Sclerosis-A Systematic Review. *J Clin Med*. 2021 Apr 9;10(8):1598. doi: 10.3390/jcm10081598.
20. Fehlings D, Krishnan P, Ragguett RM, deVeber G, Gorter JW, Hunt C, Kim M, Mesterman R, McCormick A; CP-NET Group. Neurodevelopmental profiles of children

with unilateral cerebral palsy associated with middle cerebral artery and periventricular venous infarctions. *Dev Med Child Neurol*. 2021 Jun;63(6):729-735. doi: 10.1111/dmcn.14818.

21. Ferdiana A, **Post MWM**, Bültmann U, van der Klink JJL. Barriers and facilitators for work and social participation among individuals with spinal cord injury in Indonesia. *Spinal Cord*. 2021 Oct;59(10):1079-1087. doi: 10.1038/s41393-021-00624-6.
22. Ferro MA, Lipman EL, Van Lieshout RJ, Timmons B, Shanahan L, **Gorter JW**, Georgiades K, Boyle M. Cohort Profile: Multimorbidity in Children and Youth Across the Life-course (MY LIFE) Study. *J Can Acad Child Adolesc Psychiatry*. 2021 May;30(2):104-115.
23. Ferro MA, Meyer SB, Yessis J, Reaume SV, Lipman E, **Gorter JW**. COVID-19-Related Psychological and Psychosocial Distress Among Parents and Youth With Physical Illness: A Longitudinal Study. *Front Psychiatry*. 2021 Oct 28;12:761968. doi: 10.3389/fpsy.2021.761968. eCollection 2021.
24. **Fischer MJ**, **Ketelaar M**, Van der Veere PJ, **Verhoef M**, Wadman RI, **Visser-Meily JMA**, van der Pol WL, **Schröder CD**. Illness Perceptions in Pediatric Spinal Muscular Atrophy: Agreement between Children and their Parents, and its Association with Quality of Life. *J Dev Phys Disabil*. 2021; 33: 297-310. doi: 10.1007/s10882-020-09749-7.
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26. Galvis Aparicio M, Carrard V, Kunz S, Morselli D, **Post MWM**, Peter C. Longitudinal changes in psychological adaptation outcomes during spinal cord injury inpatient rehabilitation. *Rehabil Psychol*. 2021 Nov;66(4):491-506. doi: 10.1037/rep0000396.
27. **Gorter JW**, Amaria K, Kovacs A, Rozenblum R, Thabane L, Galuppi B, Nguyen L, Strohm S, Mahlberg N, Via-Dufresne Ley A, Marelli A; CHILD-BRIGHT READYorNot™ Brain-Based Disabilities Trial Study Group; CHILD-BRIGHT READYorNot(TM) Brain-Based Disabilities Trial Study Group. CHILD-BRIGHT READYorNot Brain-Based Disabilities Trial: protocol of a randomised controlled trial (RCT) investigating the effectiveness of a patient-facing e-health intervention designed to enhance healthcare transition readiness in youth. *BMJ Open*. 2021 Mar 26;11(3):e048756. doi: 10.1136/bmjopen-2021-048756.
28. Gosselt IK, **Scheepers VPM**, Spreij LA, **Visser-Meily JMA**, **Nijboer TCW**. Cognitive complaints in brain tumor patients and their relatives' perspectives. *Neurooncol Pract*. 2020 Nov 21;8(2):160-170. doi: 10.1093/nop/npaa078. eCollection 2021 Apr.
29. Gross-Hemmi MH, Fekete C, **Post MWM**, Scheel-Sailer A, Schwegler U, Brinkhof MWG. Detecting subgroups in social participation among individuals living with spinal cord injury: a longitudinal analysis of community survey data. *Spinal Cord*. 2021 Jan 14. doi: 10.1038/s41393-020-00576-3. Online ahead of print
30. Jochems D, Van Rein E, Niemeijer M, van Heijl M, van Es MA, **Nijboer T**, Leenen LPH, Houwert RM, van Wessel KJP. Epidemiology of paediatric moderate and severe traumatic brain injury in the Netherlands. *Eur J Paediatr Neurol*. 2021 Nov;35:123-129. doi: 10.1016/j.ejpn.2021.10.004.
31. Jochems D, Van Rein E, Niemeijer M, van Heijl M, van Es MA, **Nijboer T**, Leenen LPH, Houwert RM, van Wessel KJP. Incidence, causes and consequences of moderate and severe traumatic brain injury as determined by Abbreviated Injury Score in the Netherlands. *Sci Rep*. 2021 Oct 7;11(1):19985. doi: 10.1038/s41598-021-99484-6.

- 32.**Halvorsen A, Pape K, **Post MWM**, Biering-Sørensen F, Mikalsen S, Hansen AN, Steinsbekk A. Participation and quality of life in persons living with spinal cord injury in Norway. *J Rehabil Med*. 2021 Jul 15;53(7):jrm00217. doi: 10.2340/16501977-2858.
- 33.**Hendrickx W, Riveros C, Askim T, Bussmann JBJ, Callisaya ML, Chastin SFM, Dean C, Ezeugwu V, Jones TM, Kuys SS, Mahendran N, Manns PJ, Mead G, Moore SA, Paul L, Pisters MF, Saunders DH, Simpson DB, Tieges Z, **Verschuren O**, English C. An Exploration of Sedentary Behavior Patterns in Community-Dwelling People With Stroke: A Cluster-Based Analysis. *J Neurol Phys Ther*. 2021 Jul 1;45(3):221-227. doi: 10.1097/NPT.0000000000000357.
- 34.**Hulst RY, Gorter JW, Voorman JM, Kolk E, Van der Vossen S, Visser-Meily JMA, Ketelaar M, Pillen S, **Verschuren O**. Sleep problems in children with cerebral palsy and their parents. *Dev Med Child Neurol*. 2021 May 15. doi: 10.1111/dmcn.14920. Online ahead of print.
- 35.**Huurneman KAM, Lankhorst IMF, Baars ECT, **Van Wijk I**, Van der Sluis CK. Opinions on rehabilitation care of young adults with transversal upper limb reduction deficiency in their transition to adulthood. *J Pediatr Rehabil Med*. 2021;14(1):103-112. doi: 10.3233/PRM-200690.
- 36.**King G, Kingsnorth S, Morrison A, **Gorter JW**, DeFinney A, Kehl B. Parents' perceptions of the foundational and emergent benefits of residential immersive life skills programs for youth with disabilities. *Res Dev Disabil*. 2021 Mar;110:103857. doi: 10.1016/j.ridd.2021.103857.
- 37.**King G, McPherson AC, Kingsnorth S, **Gorter JW**, Avery L, Rudzik A; Ontario Independence Program Research (OIPR) Team. Opportunities, experiences, and outcomes of residential immersive life skills programs for youth with disabilities. *Disabil Rehabil*. 2021 Sep;43(19):2758-2768. doi: 10.1080/09638288.2020.1716864.
- 38.**Klinkhammer S, Horn J, **Visser-Meily JMA**, Verwijk E, Duits A, Slooter AJC, Van Heugten CM; NeNeSCo study group. Dutch multicentre, prospective follow-up, cohort study comparing the neurological and neuropsychological sequelae of hospitalised non-ICU- and ICU-treated COVID-19 survivors: a study protocol. *BMJ Open*. 2021 Oct 7;11(10):e054901. doi: 10.1136/bmjopen-2021-054901.
- 39.**Kouwijzer I, Valent LJM, **Post MWM**, Wilders LM, Grootoink A, van der Woude LHV, de Groot S. The course of physical capacity in wheelchair users during training for the HandbikeBattle and at one-year follow-up. HandbikeBattle group. *Am J Phys Med Rehabil*. 2021 Sep 1;100(9):858-865. doi: 10.1097/PHM.0000000000001658.
- 40.**Kramer JM, **Gorter JW**. Factors influencing participation. *Disabil Rehabil*. 2021 Oct 22:1-2. doi: 10.1080/09638288.2021.1994027. Online ahead of print.
- 41.**Kramer N, Nijhof SL, van de Putte EM, **Ketelaar M**, Grootenhuis MA, van der Ent K, Swart JF, van Grotel M, Dalmeijer GW, Nap-van der Vlist MM. Role of parents in fatigue of children with a chronic disease: a cross-sectional study. *BMJ Paediatr Open* 2021 May 21;5(1):e001055. doi: 10.1136/bmjpo-2021-001055.
- 42.**Kruitwagen-Van Reenen ET, Scholten EWM, van Groenestijn A, Van den Berg LH, **Post MWM**, **Visser-Meily J**. Participation and autonomy in the first 10 months after diagnosis of ALS: a longitudinal study. *Amyotroph Lateral Scler Frontotemporal Degener*. 2021 Mar 8:1-9. Online ahead of print
- 43.**Kuiper H, Van Leeuwen CCM, Kopsky DJ, **Stolwijk-Swüste JM**, **Post MWM**. Post-traumatic stress disorder symptoms and pain intensity in persons with spinal cord

injury. *Spinal Cord*. 2021 Mar;59(3):328-335. doi: 10.1038/s41393-020-00599-w.

- 44. Kuiper H, Van Leeuwen CMC, Stolwijk-Swüste JM, Post MWM.** Reliability and validity of the Brief Illness Perception Questionnaire (B-IPQ) in individuals with a recently acquired spinal cord injury. *Clin Rehabil*. 2021 Nov 24;2692155211061813. doi: 10.1177/02692155211061813. Online ahead of print.
- 45. Kunz S, Carrard V, Galvis Aparicio M, Scheel-Sailer A, Fekete C, Lude P, Post MWM, Westphal M.** Longitudinal measurement invariance of the international spinal cord injury quality of life basic data set (SCI-QoL-BDS) during spinal cord injury/disorder inpatient rehabilitation. *Quality of Life Research*. 2021 Nov 3. doi.org/10.1007/s11136-021-03027-5. Online ahead of print
- 46. Lee V, Albaum C, Tablon Modica P, Ahmad F, Gorter JW, Khanlou N, McMorris C, Lai J, Harrison C, Hedley T, Johnston P, Putterman C, Spoelstra M, Weiss JA.** The impact of COVID-19 on the mental health and wellbeing of caregivers of autistic children and youth: A scoping review. *Autism Res*. 2021 Dec;14(12):2477-2494. doi: 10.1002/aur.2616.
- 47. Li L, Carter N, Ploeg J, Gorter JW, Strachan PH.** The role of family adaptation in the transition to adulthood for youth with medical complexity: a qualitative case study protocol. *Journal of Transition Medicine*. 2021; 07 Oct 2021. <https://doi.org/10.1515/jtm-2021-0005> Published online.
- 48. McColl J, Semalulu T, Beattie KA, Alam A, Thomas S, Herrington J, Gorter JW, Cellucci T, Garner S, Heale L, Matsos M, Batthish M.** Transition Readiness in Adolescents With Juvenile Idiopathic Arthritis and Childhood-Onset Systemic Lupus Erythematosus. *ACR Open Rheumatol*. 2021 Apr;3(4):260-265. doi: 10.1002/acr2.11237.
- 49. Mian Q, Rumsey DG, Verschuren O, Moez EK, Roy M, Kaup C, Pritchard L.** Reference Values for the Six Minute Walk Test in Children with Juvenile Idiopathic Arthritis. *Phys Occup Ther Pediatr*. 2021 Jun 24:1-11. doi: 10.1080/01942638.2021.1934239. Online ahead of print.
- 50. Mol TI, Van Bennekom CAM, Schepers VPM, Ter Hoeve N, Kruitwagen-van Reenen ET, Visser-Meily JMA, Post MWM.** Differences in societal participation across diagnostic groups: Secondary analyses of eight studies using the Utrecht Scale for Evaluation of Rehabilitation-Participation. *Arch Phys Med Rehabil*. 2021;102:1735-45. doi: 10.1016/j.apmr.2021.02.024.
- 51. Mol TI, Van Bennekom CAM, Scholten EWM, Visser-Meily JMA, Reneman MF, Riedstra A, De Groot V, Meijer JWG, Bult MK, Post MWM.** Self-regulation as rehabilitation outcome: what is important according to former patients? *Disabil Rehabil*. 2021 Nov 6;1-7. doi: 10.1080/09638288.2021.1998663. Online ahead of print.
- 52. Moll I, Voorman JM, Ketelaar M, Van Schie PEM, Gorter JW, Lequin MH, De Vries LS, Vermeulen RJ.** Prognostic value of brain abnormalities for cognitive functioning in cerebral palsy: A prospective cohort study. *Eur J Paediatr Neurol*. 2021 May;32:56-65. doi: 10.1016/j.ejpn.2021.03.010.
- 53. Nguyen L, Cross A, Rosenbaum P, Gorter JW.** Use of the International Classification of Functioning, Disability and Health to support goal-setting practices in pediatric rehabilitation: a rapid review of the literature. *Disabil Rehabil*. 2021 Mar;43(6):884-894. doi: 10.1080/09638288.2019.1643419.
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pressure in adults with cerebral palsy: a systematic review and meta-analysis of individual participant data. *J Hypertens*. 2021 Oct 1;39(10):1942-1955. doi: 10.1097/HJH.0000000000002912.

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- 56.**Nguyen L, Davis H, Bellefeuille S, Havens J, Jack SM, Di Rezze B, **Ketelaar M, Gorter JW**. Canadian resources for siblings of youth with chronic health conditions to inform and support with healthcare management: A qualitative document analysis. *Front Rehabil Sc: Families and Functioning in Childhood and Adolescence issue*. 2021; 05 Oct 2021. doi: 10.3389/fresc.2021.724589.
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- 58.**Nijhuis W, Franken A, Ayers K, Damas C, Folkestad L, Forlino A, Fraschini P, Hill C, Janus G, Kruse R, Wekre LL, Michiels L, Montpetit K, Panzeri L, Porquet-Bordes V, Rauch F, Sakkers R, Salles JP, Semler O, Sun J, To M, Tosi L, Yao Y, Yeung EHK, Zhytnik L, Zillikens MC, **Verhoef M**. A standard set of outcome measures for the comprehensive assessment of osteogenesis imperfecta. *Orphanet J Rare Dis*. 2021 Mar 20;16(1):140. doi: 10.1186/s13023-021-01682-y.
- 59.**Nijssen B, Verberne DPJ, **Visser-Meily JMA, Post MWM**, De Kort PLM, Van Heugten CM. Temporal evolution and predictors of subjective cognitive complaints up to 4 years after stroke. *J Rehabil Med*. 2021 May 5. doi: 10.2340/16501977-2840. Online ahead of print.
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- 61.**Pei J, Reid-Westoby C, Siddiqua A, Elshamy Y, Rorem D, Bennett T, Birken C, Coplan R, Duku E, Ferro MA, Forer B, Georgiades S, **Gorter JW**, Guhn M, Maguire J, Manson H, Santos R, Brownell M, Janus M. Teacher-Reported Prevalence of FASD in Kindergarten in Canada: Association with Child Development and Problems at Home. *J Autism Dev Disord*. 2021 Feb;51(2):433-443. doi: 10.1007/s10803-020-04545-w.
- 62.**Pozniak K, Buchanan F, Cross A, Crowson J, Galuppi B, Grahovac D, **Gorter JW, Hlyva O, Ketelaar M, Kraus de Camargo O, Krpan Mesic M, Martens R, McCauley D, Nguyen L, Palisano RJ, Phoenix M, Putterman C, Rosenbaum P, Sprung J, Strohm S, Teplicky R, Thomson D, Wright M**. Building a culture of engagement at a research centre for childhood disability. *Res Involv Engagem*. 2021 Nov 6;7(1):78. doi: 10.1186/s40900-021-00319-5.
- 63.**Reinhardt JD, Fellinghauer CS, **Post MWM**. Change in environmental barriers experienced over a 5-year period by people living with spinal cord injury in Switzerland: a prospective cohort study. *Spinal Cord*. 2021 Apr;59(4):441-451. doi: 10.1038/s41393-020-00580-7.
- 64.**Roels EH, Reneman MF, **Post MWM**. Measurement Properties of the Full and Brief Version of the Work Rehabilitation Questionnaire in Persons with Physical Disabilities. *J Occup Rehabil*. 2021 Dec;31(4):886-894. doi: 10.1007/s10926-021-09973-8.

- 65.**Sadiqi S, Muijs SPJ, Renkens JJM, **Post MW**, Benneker LM, Chapman JR, Kandziora F, Schnake KJ, Vialle EN, Vaccaro AR, Oner FC. Development and reliability of the AOSpine CROST (Clinician Reported Outcome Spine Trauma): a tool to evaluate and predict outcomes from clinician's perspective. *Eur Spine J.* 2021 Sep;30(9):2631-2644. doi: 10.1007/s00586-020-06554-w.
- 66.**Sadiqi S, **Post MW**, Hosman AJ, Dvorak MF, Chapman JR, Benneker LM, Kandziora F, Rajasekaran S, Schnake KJ, Vaccaro AR, Oner FC. Reliability, validity and responsiveness of the Dutch version of the AOSpine PROST (Patient Reported Outcome Spine Trauma). *Eur Spine J.* 2021 Sep;30(9):2631-2644. doi: 10.1007/s00586-020-06554-w.
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- ▶ **Verhoef M**, **Dik P**, **Vinck A**, **Maathuis P**, **Bloemen M**, **Schoenmakers M**. Spina bifida. In: **Hadders-Algra M**, **Pangalila RF**, **Becher JG**, **van der Burg JJW**, **Hielkema T**, **de Moor J** (red), *Kinderrevalidatie*, 6de druk. Assen: Koninklijke van Gorcum, 2021, p 437-458. ISBN: 978-90-232-5776-9
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- ▶ **Voorman J**, **Buizer A**, **Schouten-van Meeteren N**, **Partanen M**. Kanker op de kinderleeftijd. In: **Hadders-Algra M**, **Pangalila RF**, **Becher JG**, **van der Burg JJW**, **Hielkema T**, **de Moor J** (red), *Kinderrevalidatie*, 6de druk. Assen: Koninklijke van Gorcum, 2021, p 307-322. ISBN: 978-90-232-5776-9

- ▶ **Wijk I**, Janssen W, Elzinga-Plomp A, Sakkers R. Aangeboren en verworven aandoeningen van armen en benen. In: Hadders-Algra M, Pangalila RF, Becher JG, van der Burg JJW, Hielkema T, de Moor J (red), Kinderrevalidatie, 6de druk. Assen: Koninklijke van Gorcum, 2021, p 489-512. ISBN: 978-90-232-5776-9
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Scientific congresses (presentations, posters)

- ▶ Aalbers V, Rapuc S, Dudink J, Tataranno M, **Ketelaar M**, de Bijl-Marcus K, Benders M. Parental perceptions on the value of neonatal brain MRI. Presentation at 4th Congress of Joint European Neonatal Societies: Brain, Development and Imaging, Oct 2021. Pediatric Research; 90(suppl 1): 7.
- ▶ **Baardman J, Janssen J, Collet A, Van Langeveld S, Stolwijk-Swüste J**. Making of a mixed-reality e-learning module for patients with SCI. Poster presentation (award poster). Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ Bakkum A, Alsem M, **Ketelaar M**, Willemsen A. Exploring the 'Shared' in Shared Decision Making in Child Health: What Are the Roles of Parents and Professionals? Poster presentation for the European Academy of Childhood Disability Europe 2021. May 27, 2021.
- ▶ Bourgain M, Brochard S, Chatelin A, De La Cruz J, Dheilley E, **Gorter JW, Ketelaar M**, Mensah J, Pons C, Randazzo L, Toumi A. Accelerating INNOVation FOR CHILDren with disabilities: Creation/ Co-education of an EU e-body, presentation of the Innov4child project. Oral Presentation for the European Academy of Childhood Disability Europe 2021. May 27, 2021.
- ▶ **Bult M, Ketelaar M**, Willems-op het Veld M, **Faas E, Voorman J**, PERRIN study group. PERRIN Next Step: Better Together from Knowledge to Active practice. Poster presentation for the Dutch Congress Of Rehabilitation Medicine, Nov 11, 2021.
- ▶ Coker J, Tate D, **Post M**, Rohn E, Forcheimer M, New P, Charlifue S, Greve J. Measuring quality of life after SCI: Key findings from a validation study of the International SCI Quality of life Basic Data Set. Instructional course. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ **Crul T**, Bogerd S, **Visser-Meily A, Post M, Stolwijk-Swüste J**. Pain in SCI during initial inpatient rehabilitation: data from the Dutch SCI database. Talking poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ Das-Gupta Z, Mekking D, Nijhuis W, **Verhoef M**. Key4OI – Outcome measures in Osteogenesis Imperfecta (OI), pilot and standard set accreditation. Oral presentation for the ICHOM Global Virtual Congress 2021. Nov 10, 2021.
- ▶ **De Rooij IJM**, Van de Port IGL, Punt M, Abbink-van Moorsel PJM, Kortsmid M, van Eijk RPA, **Visser-Meily JMA, Meijer JWG**. Effect of virtual reality gait training on participation in survivors of subacute stroke: a randomized controlled trial. Abstract presentation. VR4REHAB Conference – from ideas to reality. Virtual, 24 June, 2021.
- ▶ Dontje ML, **Kruitwagen ET, Visser-Meily JMA, Beelen A**. Evaluation of the nation-wide implementation of ALS Home monitoring & Coaching; an e-health innovation for personalized care for patients with ALS. Poster presentation for the 32nd International Symposium on ALS/MND. Dec 9, 2021.
- ▶ Faber W. **Stolwijk-Swüste J**, Nachtgaal J, van Ginkel F, Zoetendal E, Winkels R, Witteman B. Faecal microbionics in patients with neurogenic bowel dysfunction and SCI or MS. A systematic review. Poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.

- ▶ **Helleman J, Bakers JNE, Pirard E, Visser-Meily JMA, van den Berg LH, Beelen A.** Reliability and feasibility of unsupervised vital capacity testing at home in patients with MND. Oral presentation for the 32nd International Symposium on ALS/MND, Dec 10, 2021
- ▶ **Helleman J, Bakers JNE, Visser-Meily JMA, van den Berg LH, Beelen A.** Validity and feasibility of unsupervised home-based vital capacity testing in patients with MND. Oral presentation for the Dutch Congress of Rehabilitation Medicine, Nov 11, 2021.
- ▶ Kennedy P, Conroy E, Heverin M, Leroi I, **Beelen A, van den Berg L, Hardiman O, Galvin M.** 'It refocuses the mind on the important things in life': an exploration of burden and self-described positive experiences of informal ALS caregivers in Ireland and the Netherlands. Poster presentation for the 32nd International Symposium on ALS/MND. Dec 10, 2021.
- ▶ **Ketelaar M.** Family engagement in research. Invited Presentation at the IV conference of the Latin American Academy of Child Development and Disability (ALDID), "Collaborating with a world in transition". Online, 12-13 Nov 2021.
- ▶ **Kuiper H. Van Leeuwen C, Stolwijk-Swüste J, Post M.** Illness perception representations during admission and discharge of SCI rehabilitation. Poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ Meeteren KM, Patty NJS, Verdonk M, Doeleman S, Willems AM, **Ketelaar M, Schuengel C.** Burn-out among parents of children with complex care needs: a case study of partnering in research. Oral Presentation for the European Academy of Childhood Disability Europe 2021. May 27, 2021.
- ▶ **Michielsen A, Van Wijk I.** Running-Based Anaerobic Performance of Dutch Children Using Lower Limb Prosthesis, presentation at the ACPOC meeting, online April 23, 2021
- ▶ **Mol TI, Van Bennekom C, Scholten EWM, Post MWM.** Een nieuw meetinstrument voor eigen regie gericht op een revalidatie populatie: SeRA = Self-Regulation Assessment. Oral presentation. Dutch Congress of Rehabilitation Medicine. Online, November, 2021.
- ▶ **Mol TI, Van Bennekom C, Scholten EWM, Post MWM.** A novel Self-Regulation Assessment (SeRA) for a rehabilitation population. Poster, International Society for Quality of Life Research Annual conference. Online, October, 2021.
- ▶ Nguyen L, Davis H, Bellefeuille S, **Ketelaar M, Di Rezze B, Jack S, & Gorter JW** in partnership with the Sibling Youth Advisory Council. Growing and Learning Together: The Process and Outcomes of Partnering with Siblings to Design a Doctoral Patient-Oriented Research Study on Health Care Transition. Oral Presentation for the European Academy of Childhood Disability Europe 2021. Online, May 27, 2021.
- ▶ Nguyen L, Bellefeuille S, Davis H, Arafah D, **Ketelaar M, Di Rezze B, Jack S, Gorter JW** in partnership with the Sibling Youth Advisory Council. Let's Go Forward Together: Strengths, Challenges, and Considerations in the Use of Social Media with Sibling Partners in Research. Demonstration Poster at the American Academy for Cerebral Palsy and Developmental Medicine. Hybrid Quebec, Canada, October 6-9, 2021.
- ▶ Osterthun O, Postma K, Van den Berg-Emons R, **Stolwijk-Swüste J, Tepper M. Post M.** Mobility level after SCI and health, functioning and well-being. Poster presentation. Annual meeting of the International Spinal Cord Society. Online October 1-3, 2021.
- ▶ Pater R, Voet N, **Beelen A, van de Geest A, Kruitwagen-van Reenen E, Houwen - van Opstal S.** De Huidige Knelpunten in de Zorg voor Neuromusculaire Aandoeningen in Relatie tot een Netwerk: Een Kwantitatieve Studie. Poster presentation for the Dutch Congress of Rehabilitation Medicine, Nov 11, 2021
- ▶ **Post M.** Development of the International SCI Psychological functioning Basic Data Set. Talking poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ **Post MWM.** Comparison of life satisfaction in persons with spinal cord injury living in 22 countries with different economic status. Oral presentation. Annual

meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.

- ▶ **Post M**, Duff J, **Kuiper H**, **van Leeuwen C**. How to measure patient's beliefs about their spinal cord injury during first rehabilitation and apply the results? Workshop. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ **Poublon C**, **Scholten EWM**, **Post MWM**, **Stolwijk-Swüste J**, Wyndaele M. Changes in bladder management during inpatient rehabilitation after spinal cord injury and determining factors: data from the Dutch Spinal Cord Injury Database. Poster and oral presentation, International Continence Society. Online, September, 2021.
- ▶ **Poublon C**, **Scholten E**, Wyndaele M, **Post M**, **Stolwijk-Swüste J**. Bladder management in SCI during inpatient rehabilitation: data from the Dutch SCI database. Poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ Prins M, Keijsers N, Zwijgers E, van Bladel A, Hijmans J, Gerards M, **De Rooij I**. Boosting Performance With High-End Interactive Gait Rehabilitation Technology. Mini-symposium. Dutch Congress of Rehabilitation Medicine. Online, 12 November, 2021.
- ▶ Roels E, Schneider C, Reneman , **Post M**. Content validity of the Work Rehabilitation Questionnaire for persons with SCI: a mixed methods study. Talking poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021
- ▶ Santana CAS, **Ketelaar M**, Rosenbaum P, de Campos AC. Research about us with us: using a participative methodology in research to approximate evidence to users in developing countries. Poster presentation for the European Academy of Childhood Disability Europe 2021. May 27, 2021.
- ▶ Santana CAS, Volski J, **Ketelaar M**, Rosenbaum P, de Campos AC. Relevant themes during the transition to adulthood according to young people with cerebral palsy partners in research. Presentation at the IV conference of the Latin American Academy of Child Development and Disability (ALDID), "Collaborating with a world in transition". Online, 12-13 Nov 2021.
- ▶ Schakel M, **Michielsen A**, Houdijk H, **Verschuren O**, **Van Wijk I**. Differences in Running Performance in Children Using a Lower Limb Prosthesis Compared to their Peers, presentation at the ACPOC meeting, online April 24, 2021. Winner of the Young Investigator Award.
- ▶ **Scholten E**, **Post M**, Van Bennekom C, Nachtegaal J, Osterthun R, Roels E, **Stolwijk-Swüste J**. Evaluation and revision of the Dutch SCI Database. Poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ **Scholten E**, **Post M**, Van Bennekom C, Nachtegaal J, Osterthun R, Roels E, **Stolwijk-Swüste J**. The Dutch spinal cord injury database. Poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 30 - October 2, 2021.
- ▶ Sloots M, **Kruitwagen ET**, **Visser-Meily JMA**, **Beelen A**: Information needs and preferences in ALS patients in the Netherlands. Poster presentation for the Dutch Congress of Rehabilitation Medicine, Nov 11, 2021
- ▶ Sloots M, **Kruitwagen ET**, **Visser-Meily JMA**, **Beelen A**: Information needs and preferences in ALS patients in the Netherlands. Poster presentation for the 32nd International Symposium on ALS/MND, Dec 9, 2021
- ▶ **Sommers-Spijkerman M**, **Kruitwagen-van Reenen E**, Zwarts-Engelbert A, Kavanaugh MS, **Beelen A**. Towards family-centered ALS care: Development of a guide for ALS care professionals on how to support parents and children in families living with ALS. Poster presentation for the 32nd International Symposium on ALS/MND, Dec 10, 2021
- ▶ **Sommers-Spijkerman M**, Rave N, **Kruitwagen-van Reenen E**, **Visser-Meily A**, Kavanaugh M, **Beelen A**: Family adjustment to amyotrophic lateral sclerosis: Transformations, struggles and needs. Oral presentation for the Dutch Congress of Rehabilitation Medicine, Nov 11, 2021.

- ▶ Stam PCC van, **Oude Lansink ILB**, Schafrat ECWM, Prins SD, Mocking M, **Ketelaar M**. The impact of COVID-19 pandemic on families of children with SMA: Parents' experiences. Oral Presentation for the European Academy of Childhood Disability Europe 2021. May 20, 2021.
- ▶ **Stolwijk-Swüste J**. Mini-symposium Virtual, Augmented en Mixed Reality: treatment or just a gadget? Chair. Dutch Congress of Rehabilitation Medicine. Online, 11 November, 2021.
- ▶ **Stolwijk-Swüste J**. Mixed Reality patient education module in spinal cord injury: 'the making of' and results of a pilot study. Oral presentation. Dutch Congress of Rehabilitation Medicine. Online, 11 November, 2021.
- ▶ **Stolwijk-Swüste J**. Spinal cord injuries and bowel stomas: timing and satisfaction with stoma formation and alterations in quality of life. Oral presentations. Dutch Congress of Rehabilitation Medicine. Online, 11 November, 2021.
- ▶ **Stolwijk-Swüste J**. Spinal cord injuries and bowel stomas: timing and satisfaction with stoma formation and alterations in quality of life. Oral presentations. International Spinal Cord Society. 2 October, 2021.
- ▶ Van der Veldt N, Faber W, Nachtegaal J, Witteman BJM, **Stolwijk-Swüste J**. Effective bowel management in SCI. Poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ **Van der Kemp J, Ketelaar M, Gorter JW**. Environmental factors and their association with participation outcomes in children with cerebral palsy. Poster presentation at the American Academy for Cerebral Palsy and Developmental Medicine. Hybrid Quebec, Canada, October 6-9, 2021.
- ▶ **Van Eenennaam RM**, Koppenol L, **Kruithof W, Kruitwagen-van Reenen E**, Pieters S, van Es M, van den Berg LH, **Visser-Meily JMA, Beelen A**: Discussing personalized prognosis of survival in amyotrophic lateral sclerosis: A qualitative study of patients, caregivers, and physicians. Poster presentation for the Dutch Congress of Rehabilitation Medicine, Nov 11, 2021
- ▶ **van Eenennaam RM**, Koppenol L, **Kruithof W, Kruitwagen-van Reenen E**, Pieters S, van Es M, van den Berg LH, **Visser-Meily JMA, Beelen A**: Discussing personalized prognosis of survival in amyotrophic lateral sclerosis: A qualitative study of patients, caregivers, and physicians. Oral presentation for the 32nd International Symposium on ALS/MND, Dec 8, 2021.
- ▶ **Van Ginkel F, Post MWM**, Faber WXM, Meij V, **Stolwijk-Swüste J**. Spinal cord injuries and bowel stomas: timing and satisfaction with stoma formation and alterations in quality of life. Talking poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ **Van Leeuwen C. Kuiper H, Stolwijk-Swüste J, Post M**. Self-management training in persons with SCI in the Netherlands. Talking poster presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ Westphal M, Kunz S, Galvis M, Scheel-Sailer A, Lude P, **Post M**, Fekete C, Carrard V. Internal reliability and longitudinal measurement invariance of the International SCI Quality of Life Basic Data Set over the course of first rehabilitation. Oral presentation. Annual meeting of the International Spinal Cord Society. Online, September 29- October 2, 2021.
- ▶ Wonink H, **Kruithof WJ**, Goedee HS, **Beelen A**: Limitations in activities and participation experienced by individuals with chronic inflammatory demyelinating polyneuropathy and multifocal motor neuropathy. Poster presentation for the Dutch Congress of Rehabilitation Medicine, Nov 11, 2021

Other presentations/training/workshops

- ▶ **Scholten EWM, Ketelaar M, Visser-Meily JMA, Post MWM**. Aandacht voor naasten. Vlog. Jaarcongres Geriatrie Revalidatie 'Kwaliteit en Praktijk'. Online, 29 januari 2021.
- ▶ **Ketelaar M, Lieshout E van**, Pelsma M, de Kleijn M. Samenwerking met ervaringsdeskundigen in onderzoek: Samen kom je verder! Workshop Colloquium 'Veerkracht', Nederlandse Vereniging van Revalidatieartsen, online, 16 april 2021.

- ▶ **Ketelaar M**, de Krom M. Patient participation in research. Workshop PhD-students, UMC Utrecht Brain Center. 25 juni 2021.
- ▶ **Ketelaar M**, Suir I, Boonzaaijer M. Ouderparticipatie. Workshop congres Nederlandse Vereniging voor Kinderfysiotherapie (NVFK). Zeist, 1-2 okt 2021.
- ▶ **Stolwijk-Swüste J**. Workshop Spina bifida en verouderen. Vereniging Spina Bifida en Hydrocephalus. Online, 8 juli 2021.
- ▶ **Stolwijk-Swüste J**. Nieuwe inzichten in pijn, blaas- en darmfunctie bij dwarslaesie. Jaarlijkse dwarslaesiedag van patientenvereniging DON. 16 oktober 2021.
- ▶ **Stolwijk-Swüste J**. Voorzitter en spreker. Webinar Mixed Reality in de dwarslaesierevalidatie! 26 mei 2021.

Remaining

- ▶ Meester-Delver A. Interview met **Gorter JW**. "Ik wil bijdragen aan de 'zorg van morgen' door het ontwikkelen van kennis en vooral door de implementatie van die wetenschappelijke kennis in de zorg voor kinderen met ontwikkelingsbeperkingen." *Ned Tijdschrift voor Revalidatiegeneeskunde*. 2021;5:16-19
- ▶ **Gorter JW** en **Voorman JM**. Geef kinderen zelf invloed op hun revalidatieproces. Kinderrevalidatie volgens het zes-F-woordenmodel. *Kinderarts en Samenleving*. Januari 2021: 34-37.
- ▶ **Ketelaar M**. Jongerenparticipatie in onderzoek, do's & dont's. Interview. *ZonMw. Nieuwbrief Jeugd*, Februari 2021.
- ▶ **Kruitwagen E**, Patiënten met ALS zijn voor alle therapeuten een ongelooflijk spannende groep. *FysioPraxis* oktober 2021: 16-18.
- ▶ **Nijboer T**. Van testen in een prikkelarme omgeving naar testen in de dynamiek van het dagelijks leven. Interview. *Keypoint*. 2021:2-3:12-15.
- ▶ **Scholten E**. 'Naaste, naasten, genaast'. Blog. *StudioGRZ.nl*, maart 2021.
- ▶ **Van Wijk I**. 'Project 'Net als jij': verbetering van de revalidatiezorg voor jongvolwassenen. *Kort & Krachtig!* September 2021: 20-25.
- ▶ **Visser-Meily JMA**. Column: Goedemorgen! *Hersenletsel Magazine*. Lente 2021, pgn. 7.
- ▶ **Visser-Meily JMA**. Column: Teamspirit. *Hersenletsel Magazine*. Zomer 2021, pgn. 7.
- ▶ **Visser-Meily JMA**. Column: Aanpassen is maatwerk. *Hersenletsel Magazine*. Herfst 2021, pgn. 7.
- ▶ **Visser-Meily JMA**. Column: Lang leve de structuur. *Hersenletsel Magazine*. Winter 2021, pgn. 7.