Amsterdam Kindersymposium 2026

Samen sterk: Kinderzorg in Verbinding

Programma en Abstract Boek

DeLaMar Theater

Amsterdam

30 januari 2026

Inhoudsopgave

AMSTERDAM KINDER SYMPOSIUM

DeLaMar
Amsterdam
30 januari 2026

PROGRAMMA AMSTERDAM KINDERSYMPOSIUM 2026

Samen sterk: kinderzorg in verbinding

07:30-08:45	**Registratie, koffie en thee**	
08:00-08:45	**Nutricia breakfast session (EN)**	Marnix Foyer
08:45-09:00	**Opening Amsterdam Kindersymposium 2026** *Prof. dr. Willem de Vries & moderatoren*	Mary Dresselhuyszaal
09:00-09:45	**Arts, kind en ouders: partners in zorg (NL)** *Prof. dr. Joost Frenkel & dr. Sjanna Besteman*	Mary Dresselhuyszaal
09:45-10:30	**In verbinding met jezelf: gezondheid en veerkracht (NL)** *Niek van den Adel*	Mary Dresselhuyszaal
10:30-11:00	**Koffiepauze**	
11:00-12:20	**SLAM session I (EN)**	Alle zalen
12:20-13:15	**Lunchpauze en sponsorloop**	
13:15-14:00	**Verbinding met elkaar: gezond opgroeien in een digitale wereld (NL)** *Drs. Petra de Jong*	Mary Dresselhuyszaal
14:00-15:20	**SLAM session II (EN)**	Alle zalen
15:20-15:40	**Koffiepauze**	
15:40-16:25	**In verbinding met de samenleving: hoe (social) media bijdragen aan betere zorg (NL)** *Paneldiscussie met dr. Emmy van den Boogaard, drs. Shakib Sana en dr. Lianne Mulder*	Mary Dresselhuyszaal
16:25-16:50	**SLAM Battle & Award ceremony (EN)** *Moderatoren*	Mary Dresselhuyszaal
16:50-17:00	**Afsluiting (NL)** *Prof. dr. Willem de Vries & moderatoren*	Mary Dresselhuyszaal
17:00-18:30	**Netwerkevenement**	DeLaMar Foyer

Voorwoord Prof. Dr. Willem de Vries

Inmiddels voor de vijftiende keer organiseert een commissie van jonge onderzoekers van het Emma Kinderziekenhuis, het Amsterdam Kindersymposium.

Het is traditie dat de jonge onderzoekers van onderzoeksgroepen van het Emma Kinderziekenhuis, maar ook onderzoekers van regionale ziekenhuizen en andere academische ziekenhuizen, op dit symposium hun nieuwste bevindingen presenteren. Wij zijn blij te zien dat elk jaar ook steeds meer onderzoekers uit andere regio's hun bevindingen komen delen en dat het aantal bezoekers uit het hele land toeneemt.

Wetenschappelijk onderzoek speelt een cruciale rol in de vooruitgang van de geneeskunde. Het stelt ons in staat om de diagnose en behandeling van kinderen steeds verder te verbeteren. Door middel van onderzoek krijgen we meer inzicht in mechanismen achter ziekteprocessen, leren we welke behandelingen het beste zijn voor patiënten én hun families en kunnen we zorg op maat bieden die het verschil maakt.

Ook dit jaar vindt het Amsterdam Kindersymposium weer plaats in het DeLaMar theater. Het theater, oorspronkelijk gebouwd als school, biedt de perfecte setting voor ons symposium. In de late 19e eeuw gingen kinderen hier naar school, en na de Tweede Wereldoorlog werd het gebouw omgebouwd tot theater. Deze geschiedenis maakt de locatie des te bijzonderder voor ons symposium op 30 januari, waar ook gepresenteerd en geleerd wordt.

De SLAM-presentaties vormen de ruggengraat van het symposium, de plenaire sessies zullen in het teken staan van het hoofdthema: "Samen Sterk: Kinderzorg in verbinding", een heel relevant onderwerp in een tijd waarin wij voor grote uitdagingen staan in de zorg. De commissie heeft zeer interessante sprekers uitgenodigd en mooie abstracts geselecteerd om te presenteren. Het belooft een bijzonder inspirerende en leerzame dag te worden voor iedereen.

Ik wens jullie allemaal een mooie en leerzame dag in het DeLaMar theater tijdens het Amsterdam Kindersymposium 2026.

Willem de Vries
Hoofd Emma Kinderziekenhuis van Amsterdam UMC

Voorwoord AKS commissie

Met veel enthousiasme nodigen wij u uit voor de 16e editie van het Amsterdam Kindersymposium, dat plaatsvindt in het DeLaMar Theater in Amsterdam. Het thema van dit jaar is: **'Samen sterk: Kinderzorg in verbinding'.** In een wereld die steeds kleiner lijkt te worden, staat verbinding centraal. Bewust en onbewust komen we voortdurend met elkaar in contact: via sociale media, in de spreekkamer, tussen arts en kind, ouder en zorgverlener, en in de bredere samenleving. Deze onderlinge verbondenheid biedt kansen, maar stelt ons ook voor nieuwe uitdagingen. Hoe blijven we écht in verbinding met elkaar? En hoe kunnen we die verbinding inzetten om de zorg voor kinderen verder te versterken? Met dit thema als leidraad hebben wij een inspirerend programma samengesteld met sprekers die vanuit verschillende perspectieven ingaan op samenwerking, communicatie en verbondenheid binnen en rondom de kindergeneeskundige zorg.

Nutricia sponsort de jaarlijkse **breakfast session**, waar u kunt genieten van een heerlijk ontbijt terwijl u wordt meegenomen in inspirerende lezingen over onderzoek op het gebied van pediatrische gastro-enterologie en voeding. Aansluitend verwelkomen wij **Joost Frenkel** en **Sjanna Besteman**, die zullen spreken over verbinding tussen arts, kind en ouder. Daarna neemt **Niek van den Adel** ons mee in een persoonlijk en krachtig verhaal over veerkracht en verbinding met jezelf. Na de eerste SLAM sessie zal **Petra de Jong** ons laten reflecteren op opgroeien in een wereld vol sociale media en de invloed hiervan op onze onderlinge verbondenheid. Na de tweede SLAM sessie volgt een paneldiscussie met **Emmy van den Boogaard**, **Shakib Sana** en **Lianne Mulder** over verbinding met de samenleving en de rol van (sociale) media in het verbeteren van de zorg.

Het Amsterdam Kindersymposium wordt afgesloten met een SLAM battle en prijsuitreiking voor de beste SLAM pitch. Wij kijken uit naar een inspirerende dag en hopen dat u volop zult genieten van het Amsterdam Kindersymposium 2026. Graag bedanken wij iedereen die heeft bijgedragen aan de totstandkoming van dit symposium. Samen hopen wij deze waardevolle traditie ook in de toekomst verder uit te bouwen.

De Amsterdam Kindersymposium Commissie 2025–2026
Yara Dixon, Emma Baas, Lieve Willemsen, Dook Koch, Jane Splinter, Lilianne van Stam, Eda Kabak, Larissa Heideman, Rimke de Kroon & Rosemarie de Ridder

Ontmoet de moderatoren

Amal Abdi

Amal promoveerde in 2021 op het onderwerp '*Inhibitor development in hemophilia A*', waarin zij onderzocht waarom sommige patiënten met niet-ernstige hemofilie A antistoffen ontwikkelen tegen behandeling met factor VIII. Binnenkort start zij aan het laatste jaar van de opleiding tot kinderarts, waarin zij zich verder wil verdiepen in de kinderhematologie. In haar vrije tijd kookt ze graag uitgebreid. Voor haar is samen eten een natuurlijke manier om mensen dichter bij elkaar te brengen. Diezelfde focus op verbinding ziet zij als onmisbaar in de kindergeneeskunde, waar goede zorg ontstaat wanneer kinderen, hun gezin en zorgverleners echt met elkaar in contact staan.

Sofia el Manouni el Hassani

Dagvoorzitter dr. Sofia el Manouni el Hassani is in 2021 gepromoveerd op het onderwerp *'Fecal microbiota and metabolomics as preclinical diagnostic biomarkers in neonatal microbiome-driven diseases'*. Sinds 2022 is zij in opleiding tot kinderarts in de mooie stad Amsterdam. De opleiding combineert zij met betrokkenheid bij vervolgonderzoek naar de rol van het microbioom als vroege marker voor opsporing van verschillende ziektebeelden. Hiervoor staat zij in verbinding met verschillende disciplines en ziekenhuizen. Om alle verbindingen in stand te houden, blijft zij in verbinding met zichzelf door regelmatig een yoga klasje te volgen.

Ontmoet de sprekers

Joost Frenkel & Sjanna Besteman

09:00 – 09:45 | Mary Dresselhuys zaal

Arts, kind en ouders: partners in zorg

Prof. dr. Joost Frenkel is hoogleraar Patient and Family Centered Medical Care en was tot voor kort werkzaam als kinderarts-kinderreumato-immunoloog in het Wilhelmina Kinderziekenhuis. Voor zijn indrukwekkende en langdurige bijdrage aan onderwijs, patiëntenzorg en wetenschappelijk onderzoek binnen de kindergeneeskunde is hij onlangs benoemd tot Officier in de Orde van Oranje-Nassau. Tijdens het Amsterdam Kindersymposium zal hij vanuit zijn rijke ervaring en expertise spreken over het belang van de samenwerking en verbinding tussen dokter, patiënt en ouders. Hij belicht hoe deze relatie de kwaliteit van zorg kan verbeteren en bijdraagt aan betere behandeluitkomsten voor kinderen.

Dr. Sjanna Besteman werd opgeleid tot kinderarts in het Wilhelmina Kinderziekenhuis in Utrecht. Sinds 2024 werkt zij als algemeen kinderarts in het Emma Kinderziekenhuis. Binnen haar werk als kinderarts zet zij zich lokaal en landelijk in om de aandacht en communicatieve vaardigheden m.b.t. diversiteit, inclusie en gelijkwaardigheid onder zorgprofessionals te vergroten. Tijdens het Amsterdam Kindersymposium zal ze het belang toelichten van inclusieve communicatie als onderdeel van patiënt en familiegerichte zorg.

Niek van den Adel

09:45 – 10:30 | Mary Dresselhuys zaal

In verbinding met jezelf: gezondheid en veerkracht

Niek van den Adel is ondernemer, schrijver en spreker en staat dagelijks op (inter)nationale podia met een inspirerend verhaal over wendbaarheid, weerbaarheid en veerkracht. Met een lach en een traan destilleert hij lessen vanuit zijn eigen ervaring, de bedrijven die hij ziet en de laatste wetenschappelijke inzichten. Niek is een graag geziene gast in talkshows, podcasts en op social media. Hij schreef vier boeken, richtte drie bedrijven op en reist als spreker de wereld over, en dat terwijl negentig procent van zijn lichaam niet meer werkt. Niek heeft een verhaal dat niet gaat over harder werken, maar vanuit je hart werken. Over hoe wij als mens, als team en als organisatie omgaan met verandering. Over acceptatie, verbinding en goed voor jezelf zorgen. Eén ding is zeker: je gaat straks geïnspireerd en geactiveerd de zaal uit.

Petra de Jong

13:15 – 14:00 | Mary Dresselhuys zaal

Verbinding met elkaar: gezond opgroeien in een digitale wereld

Drs. Petra de Jong is jeugdarts, arts Maatschappij en Gezondheid en voorzitter van AJN Jeugdartsen Nederland. Met haar brede ervaring binnen de jeugdgezondheidszorg zet zij zich dagelijks in om kinderen gelijke kansen te bieden, van het speciaal onderwijs tot de opvang van asielzoekers. Via de Johannes Wier Stichting en de campagne 'Tolken terug in de zorg, alstublieft' maakte zij zich hard voor mensenrechten en gelijke toegang tot zorg. Onlangs trok zij landelijk de aandacht met het ondertekenen van een brandbrief van bezorgde ouders aan de Nederlandse overheid over de schadelijke effecten van sociale media op kinderen. Tijdens het Amsterdams Kindersymposium gaat Petra dieper in op de negatieve gevolgen van sociale media voor kinderen, en wat we samen kunnen doen om hun welzijn beter te beschermen.

Paneldiscussie: Emmy van den Boogaard, Shakib Sana & Lianne Mulder

15:40 – 16:25 | Mary Dresselhuys zaal

In verbinding met de samenleving: hoe (social) media bijdragen aan betere zorg

Dr. Emmy van den Boogaard is kindergynaecoloog bij het Emma Kinderziekenhuis van Amsterdam UMC. Ze zette zich in voor betere zorg rondom menstruatieklachten en kreeg landelijke aandacht via de campagne van Linda. Op LINDA.nl schrijft Emmy columns waarin ze uiteenlopende aspecten van haar werk bespreekt: van de aanpak bij veelvoorkomende problemen zoals heftige menstruatie tot zeldzame aandoeningen. Ze gebruikt deze verhalen om taboes rondom meisjesgezondheid te doorbreken. Tijdens het symposium neemt Emmy deel aan een paneldiscussie over de rol van sociale media bij het bevorderen van het welzijn van jongeren.

Drs. Shakib Sana is huisarts en promovendus aan de Erasmus Universiteit Rotterdam. Daarnaast is hij medeoprichter van Gezondheidskloof.nl en de Twijfeltelefoon, twee initiatieven die zich inzetten om gezondheidsverschillen te verkleinen en betrouwbare, begrijpelijke informatie te bieden aan mensen met medische vragen of twijfels. Door zijn werk wil Shakib zorg toegankelijker maken voor iedereen, ongeacht hun achtergrond of opleidingsniveau. Tijdens het Amsterdams Kindersymposium neemt hij deel aan de paneldiscussie, waar hij zijn inzichten deelt over hoe we sociale media op een positieve manier kunnen inzetten om misinformatie tegen te gaan en zo gezondheidsverschillen te verminderen bijvoorbeeld middels het opnemen van filmpjes voor Dokters Vandaag.

Dr. Lianne Mulder is expert op het gebied van kansenongelijkheid in selectieprocedures voor numerus fixus-opleidingen, onderwijsongelijkheid en diversiteit onder artsen en medisch specialisten. Met haar achtergrond in sociologie en politieke wetenschappen onderzoekt zij de structurele barrières die bepaalde groepen minder toegang geven tot gelijke kansen in onderwijs en medische opleidingen. Naast haar academisch werk runt Lianne haar eigen bedrijf, Health Equity Research, waarmee zij als consultant organisaties in de medische wereld adviseert over het verkleinen van ongelijkheid. Tijdens het Amsterdams Kindersymposium neemt zij deel aan de paneldiscussie, waar ze ons vertelt over haar website *Ikspreekmeerdan*, waarop je zorgprofessionals kunt zoeken en vinden die je verder kunnen helpen met jouw zorgvraag, in de taal die bij je past.

Partners

Al 125 jaar lang zorgt Nutricia voor voedingen op maat voor jong en oud. Met onze voedingen en onze support ondersteunen we zo goed mogelijk de gezondheid van talloze mensen over de hele wereld. De eerste 1000 dagen van een kind zijn essentieel voor de gezondheid, ook op latere leeftijd. Gezonde voeding is in deze periode heel belangrijk. Nutricia gelooft dat de juiste voeding, en ondersteuning daarbij, een positieve bijdrage levert aan de kwaliteit van leven. Van jong tot oud, in goede en slechte tijden.

Borstvoeding is de beste voeding voor een baby.

Pfizer: Breakthroughs That Change Patients' Lives

Pfizer is een van de grootste innovatieve geneesmiddelenbedrijven ter wereld. Wereldwijd worden er in meer dan 181 landen geneesmiddelen van Pfizer voorgeschreven en gebruikt. In 2024 hebben er over de hele wereld meer dan 414 miljoen mensen een geneesmiddel of vaccin van Pfizer gebruikt.

Met de blik op de toekomst zoeken onze wetenschappers voortdurend naar nieuwe mogelijkheden om medische doorbraken te bereiken om de levens van patiënten te verbeteren en/of te verlengen.

Onze pijplijn aan nieuwe potentiële geneesmiddelen en vaccins bevat op 4 november 2025 101 middelen in ontwikkeling.

Meer weten? Kijk eens op www.Pfizer.nl en volg ons op Twitter op @PfizerNL, LinkedIn, Instagram op Pfizernl en like ons op Facebook op pfizernederland.

Rhythm Pharmaceuticals is een toonaangevend, wereldwijd biotechbedrijf dat zich richt op de ontwikkeling van innovatieve behandelingen voor zeldzame neuro-endocriene ziekten, met name voor patiënten met hyperfagie en obesitas veroorzaakt door functieverlies in de MC4R-pathway (melanocortine-4 receptor).

Rhythm Pharmaceuticals Nederland B.V. is gevestigd in Amsterdam en werkt nauw samen met zorgprofessionals om bewustzijn te vergroten, genetische diagnostiek te stimuleren en toegang tot therapieën te verbeteren.

Het bedrijf streeft naar stigma-vrije, op de oorzaak gerichte zorg en investeert in onderzoek en klinische studies om nieuwe behandelingsopties te ontwikkelen. Door sponsoring en samenwerking ondersteunt Rhythm de introductie van baanbrekende therapieën en versterkt het lokale kennis en zorgstrategieën voor patiënten met zeldzame MC4R-pathway ziekten.

Chiesi is een familiebedrijf met een rijke geschiedenis van onderzoek en ontwikkeling van medische oplossingen om onopgeloste behoeften te vervullen. Chiesi streeft ernaar een wereld te creëren waarin het normaal is om een therapie voor alle ziekten te hebben. Als familiebedrijf leveren we innovatieve therapieën en oplossingen voor mensen die getroffen zijn door zeldzame ziekten. Ons doel is gelijke toegang te waarborgen, zodat zoveel mogelijk mensen hun meest vervullende leven kunnen leiden.

Een van de belangrijke zeldzame therapeutische gebieden zijn aangeboren stofwisselingsziekten zoals de ziekte van Fabry, cystinose en alfa-mannosidose en metabole ziekten zoals lipodystrofie.

Kyowa Kirin is een Japans bedrijf dat zich richt op het ontdekken van nieuwe geneesmiddelen die levens veranderen.

We werken aan de ontwikkeling van nieuwe antilichamen en cel-en gentherapieën voor patiënten met zeldzame ziekten.

Graag gaan we met u de dialoog aan hoe wij patiëntjes met onvervulde medische behoeften optimaal kunnen helpen.

We werken met niet-aflatende passie aan ons doel: mensen en kinderen een glimlach bezorgen.

Fresenius
COMMITTED TO LIFE

Fresenius Kabi is een wereldwijd gezondheidszorgbedrijf met expertise in klinische voeding, geneesmiddelen, infusie- en transfusietherapie die essentieel zijn voor de zorg van o.a. ernstig en chronisch zieke patiënten. Met innovatieve en betrouwbare oplossingen ondersteunen we dagelijks zorgprofessionals in het versterken van de kwaliteit en toekomstbestendigheid van de zorg. Binnen onze klinische voeding bieden wij het uitgebreide Fresubin-portfolio aan, ontwikkeld om in te spelen op uiteenlopende nutritionele behoeften en zo het herstel en de kwaliteit van leven van patiënten te ondersteunen.

puramed.
healthy spaces, happy faces

Puramed ondersteunt procedurele sedatie door lachgastoediening met het dubbelmasker

Veilig werken in de zorg begint bij de bron

Puramed is gespecialiseerd in oplossingen die zorgverleners beschermen tegen blootstelling aan anesthesiegassen en chirurgische rook op de operatiekamer. Buiten de OK, heeft Puramed een sterke focus op veilige lachgastoediening binnen de kindergeneeskunde en de Spoedeisende Hulp.

Lachgas blijft essentieel in kinderzorg en spoedzorg

Lachgas is een waardevol en effectief middel voor pijnstilling en sedatie bij kinderen. Het zorgt voor comfort, een snelle werking en een positieve zorgervaring op de SEH en binnen de kindergeneeskunde. Puramed staat volledig achter het gebruik van lachgas in de zorg.

Puramed onderscheidt zich als enige aanbieder met een totaaloplossing voor veilige lachgassedatie. Met het unieke dubbelmasker wordt lachgas direct bij de bron afgezogen, waardoor blootstelling voor zorgverleners tot een minimum wordt beperkt. Deze oplossing is gebaseerd op meer dan 40 jaar ervaring in lachgassedatie en wordt dagelijks toegepast in ziekenhuizen.

Lachgasmixers - Techniek afgestemd op de zorgpraktijk

Met de high-end lachgasmixers van Puramed kunnen zorgverleners het lachgaspercentage eenvoudig afstemmen op de patiënt en de klinische situatie. De oplossingen van Puramed sluiten naadloos aan op bestaande zorgprocessen en workflows. Zo blijven patiëntcomfort en veiligheid voor zorgverleners perfect in balans.

Puramed, zorgen voor wie zorgt. Be safe, be healthy, be happy

Proefschrift specialist

Graag stellen we ons even voor....

Wij zijn **Proefschriftspecialist!** Een bedrijf sterk gespecialiseerd in het drukken en opmaken van proefschriften. Kwaliteit, gemak en snelheid is wat veel promovendi zoeken en precies dat is wat bij ons in het DNA zit. Wij maken op een snelle en kwalitatief hoogstaande wijze proefschriften voor promovendi in heel Nederland. Met 42 jaar ervaring weten wij alle ins & outs als het aankomt op het drukken van proefschriften en andersoortige boek-producties.

Alle producties worden in-house bij onze vestiging onder de rook van Amsterdam, in Zaandam, geproduceerd. Door onze nabijheid bij zowel het VUmc als het AMC kunnen wij de boeken altijd op de korts mogelijke termijn met eigen vervoer bezorgen. Uiteraard kun je ook altijd langskomen bij ons om voorbeelden te checken, een proefdruk op te pikken of om een offerte door te nemen.

Zien we je binnenkort?

Abbott

Takeda

Nutricia breakfast session

Marnix Foyer | 8:00 – 8:45

Kom genieten van een heerlijk ontbijt terwijl u wordt meegenomen in inspirerende lezingen over onderzoek op het gebied van pediatrische gastro-enterologie en voeding. Dit jaar worden de lezingen verzorgd door Anna le Clercq en Renee Boereboom.

	Presenter	Title
1	Anna le Clercq	Growth and body composition: trajectories of preterm and term-born children
2	Renee Boereboom	Blended Diet in Pediatric Care: Perceptions and Experiences of Families and Healthcare Professionals

Overzicht Programma SLAM sessions

SLAM session I overzicht 11:00 – 12:20

MARY DRESSELHUYS ZAAL

11:00 - 12:20

Gesponsord door *Rhythm Pharmaceuticals*

	Abstract titel	Auteur
1.1	Rhythm PHARMACEUTICALS	
1.2	Evaluation of Newborn Screening for Diseases Using C5-OH as a Marker: Systematic Review of the Literature and Evaluation of 17 Years of C5-OH Screening in the Netherlands	*Ryan Aukes*
1.3	Management of spasticity in neurogenetic disorders: Amsterdam experience and European status quo	*Marije Asbreuk*
1.4	The accuracy and reliability of a chatbot to retrieve protocol information in nursing practice	*Karlijn Timmer*
1.5	Cannabidiol (Epidyolex) for behavioral problems in patients with Sanfilippo: an N-of-1 series - protocol	*Kim van Veldhuizen*
1.6	Sildenafil as a repurposed therapy for Leigh syndrome: preliminary off-label experience and design of the upcoming SIMPATHIC trial	*Tessa Braam*
1.7	A new mouse model for the leukodystrophy MLC based on a rare variant in the orphan receptor GPRC5B	*Freya Kirwan*
1.8	Risk stratification for late-onset sepsis in very preterm infants through intestinal microbiota profiling: a nationwide case-control study	*Nina Frerichs*
1.9	Statin-associated symptoms and Statin Intolerance in Children with Familial Hypercholesterolemia: Insights from 15 Years of Clinical Practice	*Fianna Kowsoleea*

MARNIX FOYER

11:00 - 12:20

	Abstract titel	Auteur
2.1	Investigating cytomegalovirus infection in an in vitro human trophoblast organoid model	*Nina Johannesson*
2.2	Ultrasound-Guided or Surgical Central Venous Access in Children? A Systematic Review	*Xavier Werner*
2.3	Together for a Healthy Start: The ERACE Study on Intergenerational Childhood Experiences	*Mark Ketelaars*
2.4	Agreement and accuracy of an automated bladder ultrasound device in children: improved performance from age two (preliminary results)	*Anita de Jong*
2.5	Analysis of EV-A71 and EV-D68 Infection in Human Neuromuscular Organoids Reveals Distinct Mechanisms of Neuromuscular Impairment	*Amber Schotting*
2.6	Outcome reporting in surgical treated sacrococcygeal teratoma in children: A systematic review towards a core outcome set	*Malou Dongen*
2.7	Facilitating Family-Centred Care at the Paediatric Intensive Care Unit: Implementation of a Bedside Family Board	*Barbara Geven*
2.8	Non-operative treatment strategy versus surgery for children with simple appendicitis - a non-inferiority randomized controlled trial (APAC trial)	*Said Bachiri*
2.9	Current international variation in clinical practice of term and late-preterm neonates at risk for early-onset sepsis: survey amongst physicians and review of guidelines (NEOSS II)	*Lobke Dijkhuizen*

CAFÉ DELAMAR

11:00 - 12:20

	Abstract titel	Auteur
3.1	And then I blacked out - A qualitative interview study on alcohol intoxication events in adolescents under 18 years old	*Louise Pigeaud*
3.2	Socioeconomic inequalities in severe paediatric asthma in the Netherlands: a geospatial analysis in a nationwide cohort	*Sarah van den Berg*
3.3	Automatic Apnea Detection and Classification Using Machine learning and Transcutaneous Electromyography of the Diaphragm	*Fabio Blom*
3.4	Parental Mental Health After Very Preterm Birth: Contributors up to Term-Equivalent Age	*Kirsten Muller*
3.5	Functional power training increases calf muscle volume in children with spastic paresis	*Babette Mooijekind*
3.6	Antibiotics in the first week of life and the association with atopic diseases at ages 9-12: a prospective cohort study	*Nora Carpaij*
3.7	Gastrocnemius medialis muscle morphology and function after lengthening surgery in adolescents with cerebral palsy	*Gaia van den Heuvel*
3.8	The effect of antenatal paracetamol on breathing effort of premature infants at birth: A pilot trial	*Timothy Panneflek*
3.9	Rationale for improving school toilet facilities in the Netherlands	*Anne ter Schure*

SLAM session II overzicht 14:00 – 15:20

MARY DRESSELHUYS ZAAL

14:00 - 15:20

Gesponsord door *Pfizer*

	Abstract titel	Auteur
4.1	Pfizer	
4.2	Triglycerides as risk factor for thrombosis in neonates	*Samier Rahimi*
4.3	Indoor mold exposure and asthma in children: a literature study	*Ravi Goes*
4.4	Faecal leucine profiles can differentiate paediatric inflammatory bowel disease from irritable bowel syndrome and functional abdominal pain.	*Lana Verstoep*
4.5	Effectiveness of vaping interventions in young people: a systematic review	*Marit Erbrink*
4.6	Effect of red blood cell transfusion on inflammatory and angiogenic pathways in patients with sickle cell disease	*Lydian de Ligt*
4.7	Barriers and facilitators of physical activity in congenital heart disease: The healthcare professional's perspective	*Rebecca Meuldijk*
4.8	TTV-loads in pediatric kidney transplantation: association with immunosuppression, HLA mismatch, age and sex	*Luna Klomp*
4.9	Neurocognitive outcomes in toddlers with Sickle Cell Disease	*Noa IJdo*

MARNIX FOYER

14:00 - 15:20

	Abstract titel	Auteur
5.1	Bronchodilator response is linked with uncontrolled moderate-to-severe childhood asthma and elevated IL-4 and IL-13	*Nariman Kotb Abbas Metwally*
5.2	Discussing parenthood and child mental well-being in adult mental health services: barriers and facilitators according to parents and professionals	*Rachel van Grootheest*
5.3	Use of stem cell-derived neural systems to elucidate the effect of antivirals on clinical and lab-adapted CMV	*Renata Vieira de Sa*
5.4	Interprofessional team meetings in the Jeroen Pit Huis: satisfaction about perceived content in parents and healthcare professionals	*Franka Roest*
5.5	Molecular Culture for diagnosing early onset neonatal sepsis: preliminary results of the EOS-CHAMPIONS study	*Jip Groen*
5.6	Neurodevelopment at 9 years of age in moderate and late preterm infants	*Lorijn de Kraker*
5.7	Effect of human milk processing in preventing CMV infection in complex human fetal intestinal mucosa organoids	*Eline Freeze*
5.8	Oxygen saturation thresholds in children with acute respiratory distress (OxyKids): a multicentre, open, parallel-group, randomised clinical trial	*Sam Louman-Slot*
5.9	Efficacy and Safety of Non-Pharmacological Treatments for Paediatric Functional Constipation: A systematic review and meta-analysis	*Anna de Geus*

Café DeLaMar

14:00 - 15:20

	Abstract titel	Auteur
6.1	A GWAS meta-analysis to uncover the molecular etiology of posterior urethral valves.	*Lisanne Vendrig*
6.2	Prediction and implementation of a machine learning model for bronchopulmonary dysplasia using vital sign data from the first seven days after birth.	*Frank Bennis*
6.3	An advanced human intestinal model for studying host-pathogen interactions, antiviral therapies, and multiorgan dynamics	*Joep Korsten*
6.4	Effective communication in pediatric palliative care from the perspectives of parents and children: A systematic review	*Leonie la Rondelle*
6.5	RHINE: A Comparison of Age at Diagnosis and Clinical Outcomes in Rare Kidney Stone Forming Diseases (ERKNET x OxalEurope)	*Laila Oubram*
6.6	External Validation of a Machine Learning Prediction Model for Late-Onset Neonatal Sepsis	*Hugo Koppens*
6.7	Insights in structure and communication within pediatric palliative care networks: a social network analysis	*Sophie Tooten*
6.8	Probiotic supplementation modulates fecal metabolites in extremely preterm infants, revealing potential mechanisms of action against necrotizing enterocolitis	*Aranka van Wesemael*
6.9	Blended Tube Feeding in Children: Parental Perspectives and Experiences	*Renee Boereboom*

Abstracts

SLAM session I abstracts

1. Mary Dresselhuys zaal

11:00 - 12:20

Gesponsord door *Rhythm Pharmaceuticals*

	Abstract titel	Auteur
1.1	Rhythm PHARMACEUTICALS	
1.2	Evaluation of Newborn Screening for Diseases Using C5-OH as a Marker: Systematic Review of the Literature and Evaluation of 17 Years of C5-OH Screening in the Netherlands	*Ryan Aukes*
1.3	Management of spasticity in neurogenetic disorders: Amsterdam experience and European status quo	*Marije Asbreuk*
1.4	The accuracy and reliability of a chatbot to retrieve protocol information in nursing practice	*Karlijn Timmer*
1.5	Cannabidiol (Epidyolex) for behavioral problems in patients with Sanfilippo: an N-of-1 series - protocol	*Kim van Veldhuizen*
1.6	Sildenafil as a repurposed therapy for Leigh syndrome: preliminary off-label experience and design of the upcoming SIMPATHIC trial	*Tessa Braam*
1.7	A new mouse model for the leukodystrophy MLC based on a rare variant in the orphan receptor GPRC5B	*Freya Kirwan*
1.8	Risk stratification for late-onset sepsis in very preterm infants through intestinal microbiota profiling: a nationwide case-control study	*Nina Frerichs*
1.9	Statin-associated symptoms and Statin Intolerance in Children with Familial Hypercholesterolemia: Insights from 15 Years of Clinical Practice	*Fianna Kowsoleea*

1.1 – Rhythm Pharmaceuticals

Opening of the SLAM session will be provided by Rhythm Pharmaceuticals

1.2 - Evaluation of Newborn Screening for Diseases Using C5-OH as a Marker: Systematic Review of the Literature and Evaluation of 17 Years of C5-OH Screening in the Netherlands | Ryan Aukes

Aukes, R. (1), Albersen, M (2), Boelen, A (2), Kluijtmans, L. A. J. (3), Visser, W. F. (4), De Vries, M. C. (5), Bosch, A. M. (1), on behalf of the C5-OH NBS Working Group

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(4) Center for Health Protection, National Institute for Public Health and the Environment (RIVM), Bilthoven, the Netherlands
(5) Department of Pediatrics, Division of Metabolic Disorders, Radboud University Medical Center, Nijmegen, the Netherlands

Rationale
In 2007, the Dutch newborn screening (NBS) program was expanded to include C5-OH as a marker to screen for three inborn errors of metabolism (IEMs): 3-methylcrotonyl-CoA carboxylase deficiency (3-MCCD), 3-hydroxy-3-methylglutaryl-CoA lyase deficiency (HMGCLD) and holocarboxylase synthetase deficiency (HLCSD).

Methods
This study evaluates the effectiveness of C5-OH as an NBS marker by analyzing data from neonates screened in the Dutch NBS program from 2007 to 2023 and by reviewing the literature on various IEMs detected by an elevated NBS C5-OH concentration worldwide.

Results
Of the 126 neonates referred on the basis of elevated C5-OH concentrations in the Netherlands, 46 were true positive cases. No missed cases in the Netherlands have been reported so far, resulting in a positive predictive value of 38.3% and a negative predictive value of 100%. Strikingly, there was notable overlap between C5-OH concentrations of true and false positive cases. The systematic review included 58 articles and showed that C5-OH concentrations of patients with different IEMs reported in the literature were insufficiently distinctive to differentiate between these diseases.

Conclusion
While C5-OH can be used to detect patients with 3-MCCD, HCLSD, and HMGCLD, its value is limited by the overlap of C5-OH concentrations between affected and unaffected neonates and among patients with different diseases. This emphasizes the need for improvement of the screening strategy and potentially the use of additional markers to increase its specificity.

1.3 - Management of spasticity in neurogenetic disorders: Amsterdam experience and European status quo | Marije Asbreuk

Asbreuk, M.A.B.C. (1,2,3), Buizer, A.I. (4,5), & Wolf, N. I. (1,2)

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Rationale
Metachromatic leukodystrophy (MLD) is a rare neurodegenerative disorder caused by biallelic pathogenic variants in the ARSA gene, leading to arylsulfatase A deficiency and sulfatide accumulation in the central and peripheral nervous system causing demyelination. Once damage is irreversible, curative treatments are ineffective, and symptom management is important to maximize comfort, especially spasticity. Treatments include oral medication, botulinum toxin, intrathecal baclofen (ITB) and selective dorsal rhizotomy (SDR). This study evaluates the effects of ITB in MLD and analyses where ITB and SDR are available for progressive neurological disorders.

Methods
Data from the MLDi registry were assessed for treatment effectiveness. An online anonymized survey, in collaboration with the ERN-RND, was distributed across Europe.

Results
Between 1997 and 2025, 19 patients with MLD received ITB treatment. Following ITB initiation, spasticity improved in all patients, and daily care goals were achieved in all 14 patients with this objective. Based on these outcomes, we investigated the availability of ITB. 50 responses from 21 countries were collected. ITB was available in 23 centres, SDR in 18. Eighteen centres used ITB for progressive neurological disorders, six SDR. Five centres treated MLD patients with ITB and two with SDR. Twenty-two centres defined individualized follow-up goals, with 10 utilizing structured instruments to evaluate outcomes.

Conclusion
This research showed that ITB treatment has beneficial effects on spasticity in MLD patients, with improved daily care and patient comfort. Additionally, our survey reveals substantial heterogeneity across Europe. These findings help identify critical gaps in care and support the broader use of ITB for MLD.

1.4 - The accuracy and reliability of a chatbot to retrieve protocol information in nursing practice | Karlijn Timmer

Karlijn S. Timmer (1), Jolanda M. Maaskant (1), Jimmy Schenk (2,3)

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(3) Amsterdam UMC, University of Amsterdam, Amsterdam, Department of Intensive Care, Amsterdam, the Netherlands.

Rationale
Nurses spend significant time searching for protocol information essential for standardized procedures. We hypothesized that a large language model (LLM) chatbot could enhance efficiency by enabling immediate retrieval of relevant protocol information from the digital hospital protocol database. This study evaluated the accuracy, consistency, and correct verification of responses generated by a LLM chatbot designed to provide nursing protocol information.

Methods
Six nurses (steering group) formulated 30 clinical scenarios and corresponding prompts for chatbot interaction. All prompts were entered by the researcher (KT) at two time points. Chatbot responses were assessed by (senior) nurses from the Amsterdam UMC specializing in digital care, research and innovation, or with chatbot interest. For each scenario, participants scored five criteria (agreement, misinformation, completeness, consistency and verification of responses) and described shortcomings.

Results
Quantitative findings showed shortcomings in chatbot performance regarding protocol alignment, misinformation, completeness, consistency, and verification. Qualitative findings indicated that chatbot responses varied in the level of detail in scenarios involving multiple protocols, negatively affecting all assessment criteria within a scenario.

Conclusion
Our results show that chatbot performance depends on scenario difficulty, reflecting the consistency and completeness of protocol information in the hospital database. The chatbot is not yet feasible for implementation, as deviations in responses could compromise patient care. Some low scores reflected participants' criticism of the hospital protocols rather than chatbot errors, suggesting underestimated results. Our findings highlight that successful chatbot deployment requires time, iterative refinement, and close collaboration between developers and end users to ensure a reliable and accurate application in practice.

1.5 - Cannabidiol (Epidyolex) for behavioral problems in patients with Sanfilippo: an N-of-1 series – protocol | Kim van Veldhuizen

van Veldhuizen, K.D.I. (1), Hosman, F.L (2,3), Bosch, A.M. (1), van Eeghen, A.M. (2.4), Brands, M.M.M.G. (1)

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Rationale
Sanfilippo syndrome (mucopolysaccharidosis type III - MPS III) is a rare genetic metabolic disorder that leads to progressive neurological and behavioral deterioration, including severe irritability, aggression, and self-injurious behaviors. These symptoms significantly affect patients and caregivers, with current treatments often being ineffective. Recent reports suggest that cannabidiol (CBD), a non-psychoactive compound from cannabis, may reduce behavioral problems in some neurodevelopmental disorders. This study investigates CBD's efficacy in treating behavioral problems in patients with Sanfilippo syndrome, using an N-of-1 trial design.

Methods
The study uses an N-of-1 trial design, where each participant undergoes multiple randomized, placebo-controlled treatment periods with CBD. Participants with a confirmed diagnosis of MPS III, aged 6 years and older and exhibiting severe behavioral symptoms will be included. Each patient will undergo multiple treatment periods consisting of CBD (up to 25 mg/kg/day) and placebo, alternating with washout phases. Primary outcomes will assess behavioral improvements using the irritability subscale of the Aberrant Behavior Checklist (ABC). Secondary outcomes include questionnaires about symptom severity, parental stress, functional outcomes, quality of life, anxiety, depression and seizure frequency. Liver enzyme levels will also be monitored.

Conclusion
This trial represents a personalized approach, where each participant acts as their own control. The N-of-1 design allows assessment of individual treatment responses, crucial in rare diseases where large-scale trials are not feasible and personalized approach is necessary for optimal treatment. This study provides valuable insights into CBD's therapeutic potential for managing severe behavioral symptoms, potentially improving quality of life for patients and their families.

1.6 - Sildenafil as a repurposed therapy for Leigh syndrome: preliminary off-label experience and design of the upcoming SIMPATHIC trial | Tessa Braam

Braam, T.A. (1,2), Müller, A.R. (1,2), Janssen, M.C.H. (3), Van de Warrenburg, B.P.C. (4), Van Karnebeek, C.D. (1,2)

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Rationale
Drug repurposing offers a rapid route to therapies for rare diseases with high unmet medical needs. The international consortium SIMPATHIC (exploiting SIMilarities in clinical and molecular PAThology) identifies shared molecular and clinical mechanisms across disorders, moving beyond the one-disease-one-drug paradigm. Sildenafil, a phosphodiesterase type 5 inhibitor, was identified as a promising candidate for Leigh syndrome (LS), the most common pediatric mitochondrial disorder, caused by pathogenic variants in mitochondrial respiratory chain complexes I, IV (SURF1), or V (MT-ATP6). LS leads to early-onset neurological decline, motor dysfunction, and premature mortality. Preclinical data suggest that PDE5 inhibition improves mitochondrial function and reduces disease burden.

Methods
A randomized, double-blind, placebo-controlled, crossover trial will start in Q2 2026 to evaluate efficacy and safety of Sildenafil in MT-ATP6–related LS. In parallel, a structured single-patient, off-label protocol was initiated for individuals with LS due to complex I, IV, or V variants and rapidly progressive disease who could not await trial inclusion. For both, systematic assessments include disease severity, motor function, patient-reported outcomes, physiological monitoring, biomarkers, and safety evaluations.

Results
Three patients have been treated to date. One died from disease progression unrelated to treatment; two showed reduced disease burden, less fatigue, and improved strength. Sildenafil was well tolerated, though ocular monitoring is advised as one patient with pre-existing visual decline experienced further decline.

Conclusion
Preliminary results suggest that Sildenafil may improve function and fatigue in LS. These findings support further evaluation within SIMPATHIC, whose co-developed master-protocol ensures scientific validity, patient relevance, and accelerates evidence-based drug repurposing across rare diseases.

1.7 - A new mouse model for the leukodystrophy MLC based on a rare variant in the orphan receptor GPRC5B | Freya Kirwan

Freya Kirwan (1), Henry F. Vischer (3), Rob Leurs (3), Marjo S. van der Knaap (1,2), Rogier Min (1,2)

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(3) Department of Medicinal Chemistry, Amsterdam Institute of Molecular and Life Sciences, Faculty of Science, Vrije Universiteit Amsterdam, Amsterdam, The Netherlands

Rationale
Megalencephalic leukoencephalopathy with subcortical cysts (MLC) is a genetic brain white matter disease (leukodystrophy) marked by chronic white matter edema. Patients develop macrocephaly starting in the first year of life, with swollen white matter and fluid-filled subcortical cysts visible on MRI. Clinical symptoms include motor dysfunction, epilepsy, and mild cognitive decline. There is no curative treatment.
MLC is typically caused by pathogenic variants in MLC1 or GLIALCAM, which encode astrocyte endfeet proteins regulating ion and water homeostasis. Recently, three patients without variants in MLC1 or GLIALCAM were found to have pathogenic variants affecting orphan G protein-coupled receptor (GPCR) GPRC5B. Since GPCRs are excellent drug targets, the identification of a GPCR involved in MLC pathogenesis could aid therapy development.

Methods
We generated a transgenic mouse model carrying the specific amino acid duplication (p.Ile176dup) observed in one of the new patients. The amino acid sequence of the 4th transmembrane segment of the receptor that harbors this duplication is conserved between human and mouse.

Results
We are currently assessing whether these mice recapitulate key features of MLC, and comparing them with an established MLC mouse model (Mlc1-null mice). We measure white matter vacuolization, brain water content, seizure susceptibility, and motor behavior. Immunofluorescence analysis will assess expression and localization of GPRC5B and MLC proteins MLC1 and GlialCAM in brains from the new mouse model.

Conclusion
Our study will yield important insight into the role of GPRC5B in MLC, and helps pinpoint whether the orphan receptor is a viable target for future therapy development.

1.8 - Risk stratification for late-onset sepsis in very preterm infants through intestinal microbiota profiling: a nationwide case-control study | Nina Frerichs

Frerichs, N.M. (1,2,3)*, de Kroon, R.R. (1,2,3)*, van Schajik, Y. (3,4), el Manouni el Hassani, S. (1), van Wesemael, A.J. (1,2,3), de Boode, W.P. (5), Cossey, V. (6), Hulzebos, C.V. (7), van den Akker, C.H.P. (8), Raets, M.M.A. (9), d'Haens, E. (10), Vijlbrief, D.C. (11), van Weissenbruch, M.M. (8), de Jonge, W.J. (4,12), de Boer, N.K.H. (3,13), van Goudoever, J.B. (2,3), Beggs, A. (14), Quraishi, M.N. (14), Budding, D. (15), Davids, M. (16), Mondal, S. (17), Acharjee, A. (17,18), Niemarkt, H.J. (19,20), & de Meij, T. (1,3). *Contributed equally to the project

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Rationale
Evidence suggests translocation of intestinal bacteria to the bloodstream as a pathway for late-onset sepsis (LOS) in preterm infants, highlighting the potential of intestinal microbiota profiling for early risk stratification. We aimed to identify and validate LOS-specific microbiota signatures.

Methods
58 LOS cases were matched 1:1 to controls across three different cohorts: Discovery cohort (DC, n=36), and Validation Cohort 1 and 2 (VC1, n=24; VC2, n=56). 16S rRNA sequencing was performed on fecal samples up to 10 days before LOS onset. Microbial composition, diversity, and differentiating features were compared between various subgroups: controls versus general LOS (all pathogens combined), controls vs. non-staphylococcal LOS vs. staphylococcal-LOS, and controls vs. E.coli-LOS. For the subgroups exhibiting the most distinct microbiota signatures relative to controls, Random Forest (RF) predictive models were trained in the DC and validated in VC1/2.

Results
Across cohorts, the greatest variation in microbiota composition was explained by LOS pathogen type (R^2=17%, $P<0.001$). Infants with non-staphylococcal and E.coli-LOS showed a temporal increase in relative abundance of Escherichia/Shigella (Figure 1). Varying numbers of Escherichia-Shigella features were associated with general LOS (n=10), non-staphylococcal LOS (n=41), and E.coli-LOS (n=51). The RF model showed the highest discriminative performance for distinguishing E.coli-LOS from controls (AUC 0.99/0.78/0.61 for DC/VC1/VC2), while its performance was lower for the multi-pathogen non-staphylococcal subgroup.

Conclusion
Our data demonstrates that fecal microbiota alterations before LOS-onset are strongly associated with the pathogen isolated from the blood culture. Particularly early detection of E.coli-LOS seems feasible by microbiota profiling, opening a window for early intervention and targeted preventive strategies.

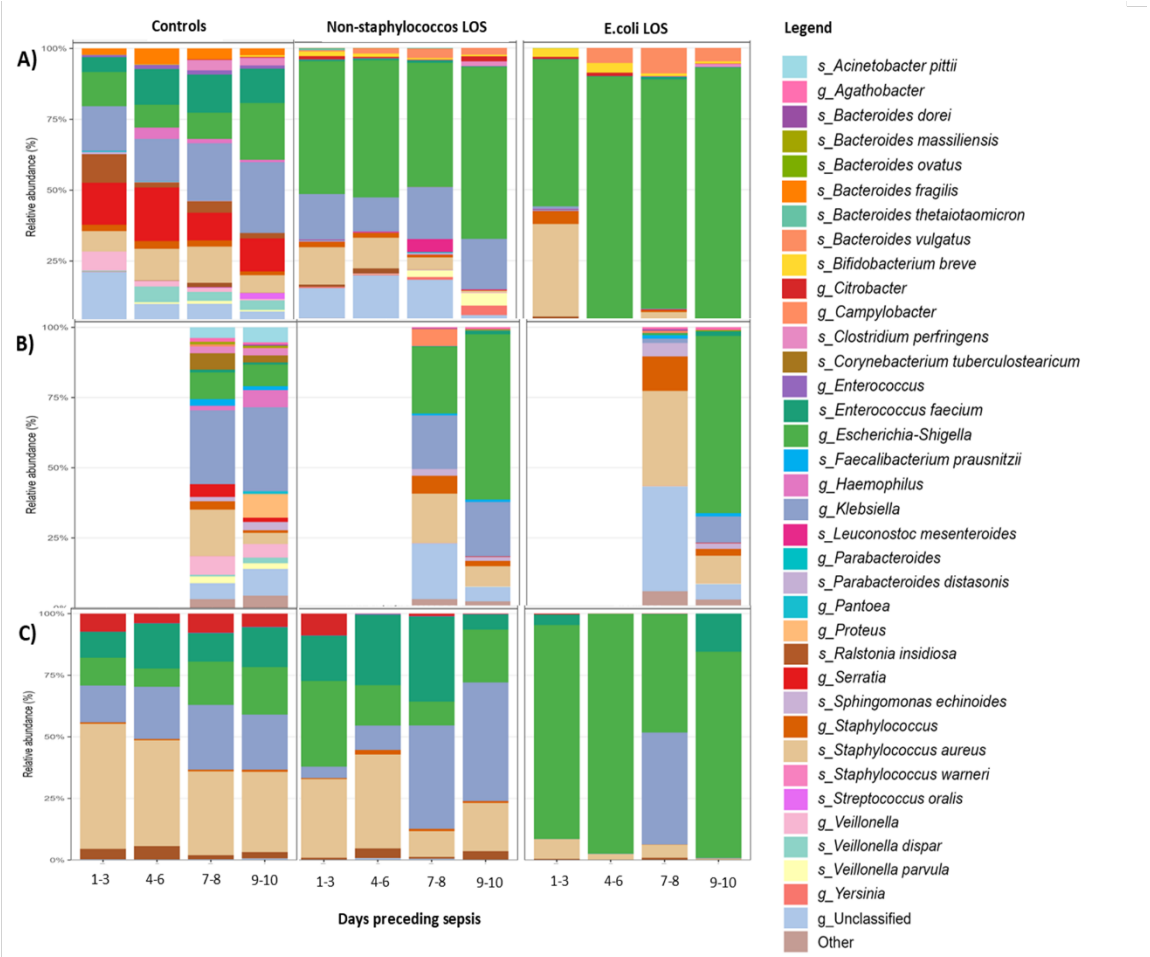

Figure 1. Temporal dynamics of gut microbiota composition at the genus level during the ten-day window preceding clinical onset of late-onset sepsis (LOS) in infants and matched controls. The figure presents stacked bar charts illustrating the relative abundance (Y-axis, %) of the 25 predominant bacterial genera across predefined time intervals, prior to LOS onset or the corresponding t=0 of the control infants (X-axis: 1–3 days, 4–6days, 7–8 days, and 9–10 days before LOS). These compositional plots were generated for the Discovery Cohort (A), Validation Cohort 1 (B), and Validation Cohort 2 (C). From left to right, panels depict the microbial composition of control infants, infants with non-staphylococcal LOS and infants with *Escherichia coli* LOS. This figure shows that focusing on subgroups based on the blood culture isolated pathogen reveals a distinct microbiota compared to controls.

1.9 - Statin-associated symptoms and Statin Intolerance in Children with Familial Hypercholesterolemia: Insights from 15 Years of Clinical Practice | Fianna Kowsoleea

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Rationale
To reduce premature cardiovascular risk in children with heterozygous familial hypercholesterolemia (FH), lipid-lowering therapy is initiated during childhood, with statins as first pharmacological step. This study aims to assess the incidence of statin-associated symptoms (SAS) and statin intolerance in pediatric FH patients.

Methods
Children (<18 years) with FH who received statins in our pediatric lipid clinic at the Amsterdam UMC between October 2009 and October 2024 were eligible. Data were retrospectively collected from electronic medical records, including medical history, statin type and dose, SAS, statin intolerance and lipid profiles. Data were assessed at three time points: statin initiation (T1), following statin dose and/or type adjustment (T2), and if changed, at the last prescribed dose (T3).

Results
696 children (47.3% girls, median age (IQR) 11.0 (8.3 – 14.0) years) were included. SAS were reported in 1 in 8.5 children at T1, 1 in 8.2 at T2, and 1 in 8.2 at T3. Most symptoms were transient and mild, with muscle symptoms without clinically significant creatine kinase elevation (≤3× upper limit of normal) most frequently reported. No cases of rhabdomyolysis or adverse events requiring hospitalization were reported. 13 children (1.9%) were statin intolerant due to persistent symptoms leading to permanent statin therapy discontinuation.

Conclusion
This study shows SAS were common, but generally transient and mild, whereas statin intolerance was relatively uncommon in children with FH. Proactive management of SAS and consideration of alternative therapies are crucial to maintain adherence and reduce ASCVD risk. Future research should focus on identifying risk factors to enable personalized treatment strategies.

Table 2 Statin-associated symptoms at three time points: at the initiation of statin therapy (T1), at the adjustment of statin therapy (either dose or type) (T2), and after the last prescribed statin dose, either at the time of data collection or upon transition to adult care (T3)

	First dose statin (T1) (N = 696)	**Adjustment of statin therapy (either dose or type) (T2) (N = 310)**	**Last prescribed statin (T3) (N = 105)**
Female sex – n. (%)	329 (47.3)	156 (50.3)	41 (39.0)
Age in years	11.0 (8.3 – 14.0)	13.1 (11.3 – 16.2)	14.9 (12.7 – 17.1)
Duration of dose in months	25 (12 – 40)	23 (11 – 39)	-
Laboratory results			
Total cholesterol (mmol/l)	6.76 (6.06 – 7.70)	5.66 (5.20 – 6.10)	5.60 (5.30 – 5.93)
Δ	-1.84 (-2.54 – -1.30)	-0.71 (-1.21 – -0.32)	-1.12 (-1.50 – -0.70)
HDL- cholesterol (mmol/l)	1.39 (1.20 – 1.60)	1.30 (1.13 – 1.54)	1.30 (1.10 – 1.52)
Δ	0.00 (-0.10 – 0.10)	-0.02 (-0.14 – 0.10)	-0.02 (-0.13 – 0.08)
LDL- cholesterol (mmol/l)	5.00 (4.38 – 5.90)	3.93 (3.63 – 4.47)	3.95 (3.70 – 4.30)
Δ	-1.80 (-2.50 – -1.31)	-0.70 (-1.23 – -0.37)	-1.12 (-1.51– -0.70)
Triglycerides (mmol/l)	0.77 (0.54 – 1.03)	0.80 (0.60 – 1.10)	0.80 (0.60 – 1.15)
Δ	-0.06 (-0.27 – 0.16)	0.00 (-0.20 – 0.20)	0.00 (-0.21 – 0.11)
ALT (U/L)	18 (15 – 23)	19 (15 – 25)	20 (15 – 27)
Δ	2 (-1 – 6)	0 (-3 – 4)	1 (-4 – 5)
AST (U/L)	27 (23 – 32)	26 (21 – 31)	26 (21 – 30)
Δ	1 (-3 – 4)	0 (-3 – 3)	0 (-2 – 4)
CK (U/L)	117 (91 – 153)	116 (86 – 157)	119 (90 – 184)
Δ	2 (-24 – 23)	2 (-27 – 33)	7 (-21 – 40)
Lipid-lowering therapy			
Children achieving LDL-cholesterol target - no. (%)	428 (61.5)	165 (53.2)	78 (74.3)
Low-intensity statin - n. (%)			
Pravastatin 10mg	4 (0.6)	-	-
Pravastatin 20mg	313 (45.0)	4 (1.3)	-
Simvastatin 10mg	3 (0.4)	-	1 (0.9)
Moderate-intensity statin - n. (%)			
Atorvastatin 10mg	2 (0.3)	1 (0.3)	-

Atorvastatin 20mg	2 (0.3)	3 (1.0)	3 (2.8)
Pravastatin 40mg	9 (1.3)	76 (24.4)	-
Rosuvastatin 5mg	210 (30.2)	10 (3.2)	-
Rosuvastatin 10mg	147 (21.1)	175 (56.5)	32 (30.5)
Simvastatin 20mg	1 (0.1)	1 (0.3)	-
Simvastatin 40mg	-	-	1 (0.9)
High-intensity statin - n. (%)			
Atorvastatin 40mg	-	1 (0.3)	-
Rosuvastatin 20mg	5 (0.7)	38 (12.2)	68 (64.2)
Rosuvastatin 40mg	-	1 (0.3)	-
Statin-associated symptoms			
Children experiencing SAS – n.	82	38	13
Muscle symptoms with CK ≤ 3x ULN – n.	42	16	3
Muscle symptoms with CK > 3x ULN ≤ 10x ULN – n.	-	-	-
No muscle symptoms with CK > 3x - ≤ 10x ULN – n.	1	5	2
ALT > 3x ULN – n.	1	-	-
AST > 3x ULN – n.	-	-	-
Gastrointestinal symptoms – n.	12	5	1
Psychiatric symptoms – n.	7	4	-
Dermatosis - n.	6	-	1
Headache - n.	7	4	1
Patients with other symptoms - n.	19	8	5
Intervention following statin-associated symptoms			
Temporary stop statin - n.	47	18	3
Statin-associated symptoms disappeared - n.	7	4	1
Dosage reduction – n.	14	13	5
Statin-associated symptoms disappeared - n.	6	5	4
Switch to second statin - n.	27	18	2
Statin-associated symptoms disappeared - n.	11	6	-
Switch to third statin - n.	7	6	-
Statin-associated symptoms disappeared - n.	6	2	-

Statin intolerant - n.	7	6	-
switch to ezetimibe monotherapy - n.	4	-	-
switch to PCSK9-i monotherapy - n.	1	1	-
switch to ezetimibe and PCSK9-i - n.	1	3	-
No lipid-lowering treatment - n.	1	2	-

All values are presented as median (interquartile range, IQR), unless otherwise specified. ALT: alanine aminotransferase; AST: aspartate aminotransferase; CK: creatine kinase; HDL-cholesterol: high-density lipoprotein cholesterol; l: liter; LDL-cholesterol: low-density lipoprotein cholesterol; mg: milligrams; mmol: millimoles; n.: number; PCSK9-i: proprotein convertase subtilisin/kexin type 9 inhibitor; SAS: statin-associated symptoms; TC: total cholesterol; TG: triglycerides; U: Units; ULN: upper limit of normal; Δ: Change (median (IQR) of lipids in period between initiation or adjustment of statin and the subsequent follow-up. Statins were classified by potency according to international guidelines[1]

[1] Grundy SM, Stone NJ, Bailey AL, Beam C, Birtcher KK, Blumenthal RS, et al. 2018 AHA/ACC/AACVPR/AAPA/ABC/ACPM/ADA/AGS/APhA/ASPC/NLA/PCNA Guideline on the Management of Blood Cholesterol: Executive Summary: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. J Am Coll Cardiol. 2019;73(24):3168-209.

2. MARNIX FOYER

11:00 - 12:20

	Abstract titel	Auteur
2.1	Investigating cytomegalovirus infection in an in vitro human trophoblast organoid model	*Nina Johannesson*
2.2	Ultrasound-Guided or Surgical Central Venous Access in Children? A Systematic Review	*Xavier Werner*
2.3	Together for a Healthy Start: The ERACE Study on Intergenerational Childhood Experiences	*Mark Ketelaars*
2.4	Agreement and accuracy of an automated bladder ultrasound device in children: improved performance from age two (preliminary results)	*Anita de Jong*
2.5	Analysis of EV-A71 and EV-D68 Infection in Human Neuromuscular Organoids Reveals Distinct Mechanisms of Neuromuscular Impairment	*Amber Schotting*
2.6	Outcome reporting in surgical treated sacrococcygeal teratoma in children: A systematic review towards a core outcome set	*Malou Dongen*
2.7	Facilitating Family-Centred Care at the Paediatric Intensive Care Unit: Implementation of a Bedside Family Board	*Barbara Geven*
2.8	Non-operative treatment strategy versus surgery for children with simple appendicitis - a non-inferiority randomized controlled trial (APAC trial)	*Said Bachiri*
2.9	Current international variation in clinical practice of term and late-preterm neonates at risk for early-onset sepsis: survey amongst physicians and review of guidelines (NEOSS II)	*Lobke Dijkhuizen*

2.1 - Investigating cytomegalovirus infection in an in vitro human trophoblast organoid model | Nina Johannesson

Johannesson, N. (1,2), Drongovskij, A. (1,2), Boussata, S. (3,4), Vieira da Sá, R. (1), Afink, G. (3,4,5) & Pajkrt, D. (1)

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Rationale
The placenta forms a powerful barrier to infections, however certain congenital pathogens, like cytomegalovirus (CMV), can be vertically transmitted to infect the fetus and cause congenital disease. Congenital CMV (cCMV) infection is the leading cause of congenital infection worldwide with a significant burden of disease. There is no cure or treatment due to lack of knowledge on cCMV pathogenesis. How CMV is transmitted across the placenta to cause cCMV disease remains poorly defined. One of the main cell types of the placenta are trophoblasts that include syncytiotrophoblasts (STBs) and extravillous trophoblasts (EVTs). We aim to investigate cCMV infection in an in vitro human trophoblast organoid (TO) model.

Methods
Human trophoblast stem cells (TSCs) were generated from first trimester human placentas. TSCs were differentiated into STBs and EVTs. TOs were generated by seeding TSCs in Matrigel droplets. TSCs, STBs, EVTs and TOs were infected with a clinical CMV isolate and viral cell tropism was determined by immunofluorescence staining. In the next step, a human TO model will be generated, combining all different cell types. The susceptibility and the innate immune response of TOs to CMV infection will be defined. Transcriptomics analysis will describe changes to the host cell upon CMV infection.

Results
CMV infection was detected in TSCs, STBs and EVTs as early as 2 days post infection. More cells were infected with CMV in the STBs compared to TSCs and EVTs.

Conclusion
CMV infection was detected in all primary fetal cells of the placenta, especially in STBs. After identification of molecular mechanisms of CMV infection in placental cells and TOs, we will evaluate anti-viral interventions. These insights will importantly contribute to the development of innovative therapeutic or preventive intervention strategies of cCMV disease.

2.2 - Ultrasound-Guided or Surgical Central Venous Access in Children? A Systematic Review | Xavier Werner

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Rationale
Central venous catheters (CVCs) are essential in pediatric care, providing long-term venous access. Traditionally, tunneled CVCs are inserted through open surgical (OS) venotomy of the internal jugular vein. More recently, ultrasound-guided (USG) percutaneous insertion has gained popularity as a minimally invasive alternative, yet comparative evidence in children remains limited.

Methods
A systematic review was conducted of randomized controlled trials (RCTs) comparing USG and OS insertion of tunneled CVCs in patients under 18 years. Searches were performed in PubMed, MEDLINE, EMBASE, the Cochrane Library, and clinical trial registries from July 2015 to July 2025. The primary outcome was successful catheter placement; secondary outcomes included procedure duration, infection, thrombosis, and venous preservation. Data extraction, risk of bias assessment, and GRADE evaluation were performed.

Results
Five RCTs from five pediatric centers enrolled 577 patients (USG = 277; OS = 300), of whom 283 (60%) were male. The mean age was 5.1 ± 3.7 years. Catheter placement success was similar between groups (97.5% USG vs 95.7% OS; RR 1.00, 95% CI 0.96–1.05; moderate-certainty evidence). Infection rates were comparable across studies (RR 0.74, 95% CI 0.40–1.38; very-low-certainty evidence). Pooled data indicated fewer thrombotic events with USG (RR 0.34, 95% CI 0.14–0.82; very-low-certainty evidence).

Conclusion
In summary, USG insertion of tunneled CVCs appears to be a safe and effective alternative to OS insertion in pediatric patients, with comparable success and infection rates and a potential reduction in thrombotic risk. However, the very-low-certainty evidence warrants confirmation in larger, well-designed trials.

2.3 - Together for a Healthy Start: The ERACE Study on Intergenerational Childhood Experiences | Mark Ketelaars

Ketelaars, M.F.M. (1,2), de Grauw, A.M. (1), Kiefte-de Jong, J.C. (2) & van Veen, M. (1)

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Rationale
Parental Adverse Childhood Experiences (ACEs) can affect health, growth, and development of children. By following newborns and their parents over a two-year period, the ERACE study aims to capture intergenerational processes regarding health and wellbeing that unfold across time and context.

Methods
ERACE represents a close collaboration between the Juliana Children's Hospital, Reinier de Graaf Hospital, the Municipality of The Hague, and the LUMC Health Campus The Hague. Children are recruited from both hospital and community care settings. The study collects extensive data on growth, nutrition, motor skills and psychosocial development, creating a rich and unique longitudinal dataset.

Results
To date, 131 families have been enrolled, and the first children have completed the full two-year follow-up. Findings show that mothers with multiple ACEs have an increased risk of pregnancy complications, and their infants show slightly reduced weight gain during the first six months of life. Furthermore, no significant association was found between physicians' ACE-risk assessments and parents' self-reported ACEs, underscoring the complexity of recognising psychosocial adversity in clinical practice and the importance of engaging parents as partners in care.

Conclusion
With a steadily growing cohort and expanding network of partners, the ERACE study will continue to investigate the intergenerational transmission of ACEs. Its value lies in the comprehensive data collection and collaborative foundation between hospitals, community health services, researchers, and families. With the first results published, ERACE will strive to follow participants throughout their childhood, in order to strengthen early identification and support for families, contributing to healthier futures for the next generation.

2.4 - Agreement and accuracy of an automated bladder ultrasound device in children: improved performance from age two (preliminary results) | Anita de Jong

Anita C. de Jong (1,2), Olga E. Arguedas Flores (3), Job B.M. van Woensel (1,2), Kristin Keunen (4), Tanja de Kraker (3), Jolanda M. Maaskant (2,5)

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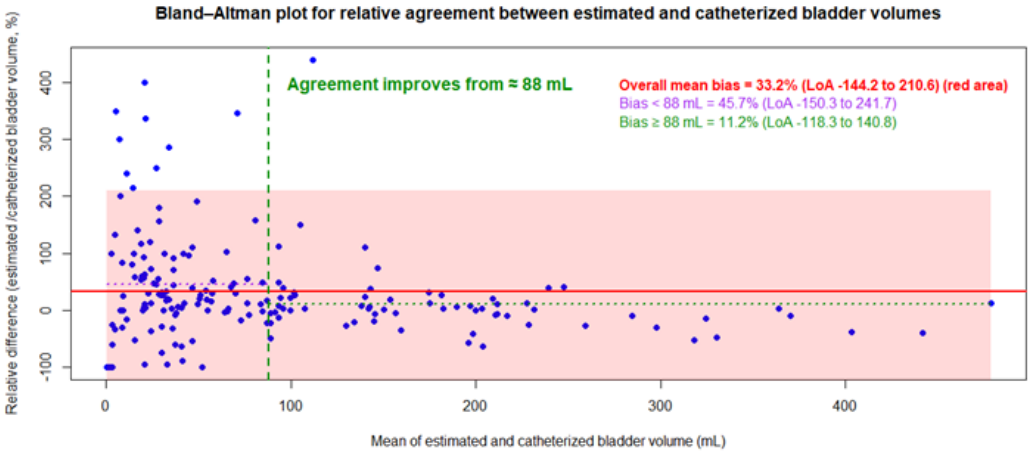
Rationale
Automated bladder ultrasound devices (ABUDs) are used in clinical practice to assess bladder volumes in patients with suspected urinary retention. However, the accuracy of ABUDs in pediatric patients is unclear. This study evaluated the agreement between ABUD-estimated and catheterized bladder volumes in children and the diagnostic accuracy for detecting urinary retention.

Methods
This cross-sectional diagnostic accuracy study included children aged <12 years at a tertiary pediatric hospital. Among patients requiring urinary catheterization, bladder volumes estimated with the ABUD 'Cubescan™ BioCon-900S' (index test) were compared with catheterized volumes (reference standard) using correlation, mean bias, and limits of agreement (LoA). Urinary retention was defined as a catheterized volume >100% of expected bladder capacity.

Results
In 183 children, 189 bladder scans were performed. The correlation between ABUD-estimated and catheterized volumes was strong (Spearman's ρ = 0.88, 95% CI 0.81–0.93). The device showed an absolute mean bias of −0.6 mL (95% LoA −98.0 to 96.8 mL) and a relative mean bias of 33.2% (95% LoA −144.2 to 210.6%). Agreement improved above ≈88 mL, reflecting a filled bladder in children ≥2 years (Fig. 1). For identifying urinary retention (n = 48), sensitivity was 0.75 (95% CI 0.60–0.86), specificity 0.90 (95% CI 0.84–0.94), and AUC 0.75.

Conclusion
The Cubescan™ BioCon-900S shows strong correlation with catheterized bladder volumes in children <12 years. Despite substantial bias, agreement improves at volumes ≥88 mL. These preliminary findings suggest that the device is suitable for estimating bladder volumes in children aged ≥2 years, particularly for detecting urinary retention.



2.5 - Analysis of EV-A71 and EV-D68 Infection in Human Neuromuscular Organoids Reveals Distinct Mechanisms of Neuromuscular Impairment | Amber Schotting

Schotting, A.J. (*,1,2), García-Rodríguez, I. (*,1,2), Freeze, E. (1,2), Wagner, M. (3), Mioch, M. (1,2), Moffelein, A. (1,2), Jackson, W. (3), Pajkrt, D. (1,2), Wolthers, K.C. (2), Vieira de Sá, R. (#,2), & Sridhar, A. (#,1,2,4). (*,# These authors contributed equally)

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Rationale
Enteroviruses A71 (EV-A71) and D68 (EV-D68) are major causes of neurological disorders, including acute flaccid myelitis (AFM), but the molecular mechanisms driving their neurovirulence and impact on neuromuscular integrity remain poorly understood. Physiologically relevant human models are needed to dissect virus-specific mechanisms of neuromuscular dysfunction.

Methods
We employed human induced pluripotent stem cell (iPSC)-derived neuromuscular organoids (NMOs) to characterize the cellular tropism and pathogenic effects of EV-A71 and EV-D68. NMOs were infected with either virus, and replication kinetics was assessed. Transcriptomic profiling identified global changes in gene expression and pathway regulation. Based on these data, we examined SNAP25 cleavage, a key SNARE protein involved in synaptic vesicle fusion, and evaluated apoptotic responses by measuring cleaved caspase-3 levels.

Results
Both viruses efficiently infected neuronal populations within NMOs, with EV-A71 exhibiting higher infectivity compared to EV-D68. Transcriptomic analysis revealed that infection with either virus led to downregulation of neuronal and muscular gene networks, with EV-A71 preferentially disrupting neuronal pathways and EV-D68 exerting a stronger effect on muscle-associated genes. Protein-level analyses showed that both viruses stochastically cleaved SNAP25 in NMOs. Additionally, infection with either virus increased cleaved caspase-3 levels, indicating activation of apoptosis.

Conclusion
These findings establish NMOs as a physiologically relevant platform for studying host–virus interactions underlying AFM and provide new insights into virus-specific mechanisms of neuromuscular dysfunction. The distinct cellular tropism and molecular effects observed for EV-A71 and EV-D68 highlight the need for targeted therapeutic strategies against enterovirus-associated neurological disease.

2.6 - Outcome reporting in surgical treated sacrococcygeal teratoma in children: A systematic review towards a core outcome set | Malou Dongen

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Rationale
Outcome reporting for surgically treated sacrococcygeal teratoma (SCT) lacks uniformity, making it challenging to compare clinical results and treatment strategies. This highlights the need for the development of a Core Outcome Set (COS) for SCT. We aimed to identify outcomes reported in studies on the surgical treatment of SCT in children.

Methods
A systematic literature search was performed in Ovid Medline, Embase, and Web of Science in October 2024. Studies were eligible if they reported outcomes of surgical treatment for SCT in children aged 0–18 years. Two independent investigators screened the titles and abstracts, followed by full-text assessment and data extraction. Reported outcomes were categorized into core areas based on the OMERACT Filter 2.0 framework: Adverse Events, Pathophysiological Manifestation, Life Impact, Resource Use, and Death. This study adhered to the 2020 PRISMA statement guidelines for systematic reviews, and the study protocol was registered in PROSPERO (CRD4202561872).

Results
Out of 1,356 identified studies, 126 met the inclusion criteria for full-text screening. More than 100 unique outcomes were identified. Most studies reported between eight and twelve outcome measures. The most prevalent outcomes were histopathology, mortality, and recurrence.

Conclusion
This systematic review reveals substantial heterogeneity in outcome reporting in SCT research, emphasizing the need for a standardized COS. These findings serve as an important first step towards a future Delphi study to establish global consensus on outcome reporting for the surgical treatment of SCT in children.

2.7 - Facilitating Family-Centred Care at the Paediatric Intensive Care Unit: Implementation of a Bedside Family Board | Barbara Geven

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Rationale
Bedside whiteboards are widely used across healthcare settings to enhance communication between healthcare professionals, patients, and families. Such tools may also promote family-centred care (FCC) is paediatric settings. This study aims to assess 1) the implementation process and, 2) effectiveness of a bedside Family Board (FB) in the Paediatric Intensive Care Unit (PICU).

Methods
A hybrid type 1 effectiveness–implementation design was employed, combining structured observations, validated questionnaires for professionals, and surveys among family members and professionals. These quantitative data were complemented by focus groups and semi-structured interviews with professionals.

Results
Healthcare professionals (n=50) reported high acceptability (MDN=4, IQR=.5), appropriateness (MDN=4, IQR=.25), and feasibility of the FB (MDN=4, IQR=.5). Results from the survey (n=42 families, n=49 professionals) and observations (n=119) indicated that the FB accurately captured child and family needs (child needs: MDN=5, IQR=1, family needs: MDN=4, IQRfam=.75, IQRprof=.1). Effectiveness outcomes showed that the FB facilitated inclusion of family perspectives (MDNfam=4, IQR=1) in care planning and shared goal setting (MDN=4, IQR=1), thereby promoting FCC. Focus groups (n=20 professionals) and interviews (n=1 professional) underscored the need for ongoing awareness, reinforcement, and integration into daily clinical workflows.

Conclusion
Implementing the FB into routine practice can enhance FCC in the PICU by fostering shared care goals and supporting caregiver involvement in daily care. Sustained implementation requires adaptation to the child's age, condition, and family context, contextual tailoring, integration within existing workflows, and continuous staff training to maintain engagement.

2.8 - Non-operative treatment strategy versus surgery for children with simple appendicitis - a non-inferiority randomized controlled trial (APAC trial) | Said Bachiri

Paul van Amstel* (1,2,3), Said Bachiri* (1,3), Max Knaapen (1), Johanna H. van der Lee (4), Rik van Eekelen (5), Willem A. Bemelman (6), Hester Rippen-Wagner (7), Taco S. Bijlsma (8), Charlotte Blanken-Peeters (9), Evert-Jan G. Boerma (10), Anne Loes van den Boom (11), Frank J.C. van den Broek (12), Huib A. Cense (13), Peter van Duijvendijk (14), Frank P. Garssen (15), Klaas H. in 't Hof (16), Vanessa J. Leijdekkers (17), Maarten A. Lijkwan (18), Gerda W. Zijp (19), Hugo A. Heij (1), Joep P.M. Derikx (1,2,3), Ernest L.W. van Heurn (1,2,3), Roel Bakx (1,2,3), Ramon R. Gorter (1,2,3), on behalf of the APAC collaborative study group

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Rationale
This study compared a non-operative treatment (NOT) strategy with appendectomy for children with simple appendicitis in terms of complications, Health-Related Quality of Life (HR-QoL), avoidance of appendectomy, and costs at 1-year follow-up.

Methods
This multi-center randomized controlled non-inferiority trial included children aged 7-17 years with imaging confirmed simple appendicitis, excluding those with a faecolith. The NOT strategy group received 48 hours of intravenous amoxicillin/clavulanic acid and gentamicin, followed by 5 days of oral amoxicillin/clavulanic acid. The primary outcome was the proportion of participants experiencing a complication within one year (non-inferiority margin of 5%). Secondary outcomes included HR-QoL, the percentage of participants not requiring appendectomy, and costs.

Results
Between January 2017 and October 2023, 302 children from 15 Dutch hospitals were randomly assigned to a NOT strategy (n=151) or appendectomy (n=151). In the Intention-to-treat population, 14/151 (9.3%) participants in the NOT strategy group versus 13/151 (8.6%) in the appendectomy group experienced a complication at 1-year follow-up (absolute risk difference: 0.7%, upper limit 95%CI: 7.1%). No difference was found in HR-QoL, appendectomy could be avoided in 105/151 (69.5%) participants and costs (both direct and societal) were lower for the NOT strategy group (mean difference €767; 95%CI: 320-1214 and €874; 95%CI: 118-1631, respectively)

Conclusion
Non-inferiority of NOT strategy for acute simple appendicitis in children could not be demonstrated. However, the absolute risk difference in proportion of participants with complications was marginal, while surgery was avoided in approximately 70% of participants. The NOT strategy was also associated with lower costs.

2.9 - Current international variation in clinical practice of term and late-preterm neonates at risk for early-onset sepsis: survey amongst physicians and review of guidelines (NEOSS II) | Lobke Dijkhuizen

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Rationale
Early-onset sepsis (EOS) is a potentially fatal and diagnostically challenging disease. Over a decade ago, the Neonatal Early-Onset Sepsis Survey (NEOSS I) revealed wide international variation in clinical practice, guideline recommendations, and adherence. Strategies to reduce unnecessary antibiotic use have since emerged, but their real-world impact remains unclear. NEOSS II reassesses current management, guidelines and adherence to detect shifts since NEOSS I.

Methods
A web-based survey was conducted among physicians in Europe, North America, and Australia. Participants responded to six clinical scenarios (cases A–F) and additional questions on EOS management. Thirteen national guidelines were reviewed and compared with survey responses.

Results
440 paediatricians from 18 countries participated. For neonates with only risk factors, 10% would start antibiotics immediately and 18% if infection markers were abnormal (NEOSS I:29%; 45%). With only clinical signs, 45% would start antibiotics immediately and 33% if markers were abnormal (NEOSS I:57%; 33%). When both risk factors and symptoms were present, 85% would start antibiotics immediately and 11% if markers were abnormal (NEOSS I:86%; 13%). Treatment was mostly <48 hours when symptoms resolved within 6 hours (73%) but varied widely if symptoms persisted 24–48 hours. Laboratory tests influenced discontinuation more than initiation (65% vs. 21%, $p<0.001$). Guidelines consistently recommended treatment for neonates with both risk factors and symptoms but varied in other scenarios.

Conclusion
EOS management has shifted toward more conservative initiation and shorter treatment durations. Persistent practice and guideline variation, particularly regarding treatment duration, highlights the need for updated, and universally applicable recommendations to optimize antibiotic stewardship.

3. Café DeLaMar

11:00 - 12:20

	Abstract titel	Auteur
3.1	And then I blacked out - A qualitative interview study on alcohol intoxication events in adolescents under 18 years old	*Louise Pigeaud*
3.2	Socioeconomic inequalities in severe paediatric asthma in the Netherlands: a geospatial analysis in a nationwide cohort	*Sarah van den Berg*
3.3	Automatic Apnea Detection and Classification Using Machine learning and Transcutaneous Electromyography of the Diaphragm	*Fabio Blom*
3.4	Parental Mental Health After Very Preterm Birth: Contributors up to Term-Equivalent Age	*Kirsten Muller*
3.5	Functional power training increases calf muscle volume in children with spastic paresis	*Babette Mooijekind*
3.6	Antibiotics in the first week of life and the association with atopic diseases at ages 9-12: a prospective cohort study	*Nora Carpaij*
3.7	Gastrocnemius medialis muscle morphology and function after lengthening surgery in adolescents with cerebral palsy	*Gaia van den Heuvel*
3.8	The effect of antenatal paracetamol on breathing effort of premature infants at birth: A pilot trial	*Timothy Panneflek*
3.9	Rationale for improving school toilet facilities in the Netherlands	*Anne ter Schure*

3.1 - And then I blacked out - A qualitative interview study on alcohol intoxication events in adolescents under 18 years old | Louise Pigeaud

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Rationale
Understanding the mechanisms influencing alcohol consumption in adolescents is crucial for developing effective strategies to minimize alcohol intoxication in this age group. This study seeks to explore the experiences of adolescents who have had an alcohol intoxication, aiming to better understand their motivations and inform the development of improved prevention strategies.

Methods
The study involved adolescents under 18 years old admitted for an alcohol intoxication at Reinier de Graaf Gasthuis in Delft, The Netherlands. Data from 24 semi-structured interviews, part of the "Youth and Alcohol" outpatient clinic's standardized follow-up program, were analysed. In-depth interviews were conducted 1–2 months after the intoxication event.

Results
Four key themes emerged from the interviews: (1) Context of alcohol consumption, (2) alcohol consumption patterns, (3) consequences of the alcohol intoxication event, and (4) reflections on the alcohol intoxication event and recommendations for preventive measures. A common observation was that many adolescents reported not recognizing when they became intoxicated, often describing a "black-out" experience. During the alcohol intoxication event, they often consume spirits in the evening/night, typically in social settings with friends, motivated by social and enhancement drinking motives. The adolescents who participated emphasised the importance of alcohol education, stricter advertising regulations, and stronger enforcement of alcohol laws as key measures to reduce alcohol intoxication and mitigating alcohol's harmful consequences in their population.

Conclusion
This study provides valuable insights into alcohol consumption patterns and consequences in adolescents who had an alcohol intoxication. It underscores the need for tailored prevention strategies, suggested by the adolescents themselves, to effectively reduce alcohol intoxication in adolescents.

3.2 - Socioeconomic inequalities in severe paediatric asthma in the Netherlands: a geospatial analysis in a nationwide cohort | Sarah van den Berg

van den Berg, S. (1,2), Hussain, T. (3), van Dormolen, S. (4), Sprinkhuizen, M. (4), Hoeijmakers, L. (4), Terheggen-Lagro, S.W.J. (3), Maitland-van der Zee, A.H. (2,5), van Woensel, J.B.M. (1), Vijverberg, S.J.H. (2,3)*, Kapitein, B. (1)*

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Rationale
Emerging evidence shows that health disparities may contribute to an increased risk of severe asthma. However, current literature is limited to regional data. Therefore, the study objectives were to assess how socioeconomic disparities influence the risk of severe paediatric asthma on a national level and explore its geographical distribution in the Netherlands.

Methods
In this nationwide cohort study, all children aged 2-17 years living in the Netherlands between 2018-2022 were included. Asthma definitions were based upon individually linked data from non-public registry databases on asthma-related health expenditures including hospital and paediatric intensive care unit (PICU) admissions. Geospatial analysis was used to identify regions with the highest counts of severe asthma ("hot spots"). Additionally, the impact of various socioeconomic variables on the primary outcome of severe asthma was assessed using a linear probability model.

Results
The total study population consisted of 4.538.020 children. Children from the lowest income class had twice the odds of severe asthma ($p<0.001$) and were 2.6 times as likely to be admitted to the PICU compared to the highest income class ($p<0.001$). Other socioeconomic disadvantage factors for severe asthma are, in order of level of association, living in a rental house, having a migration background, and having a lower socioeconomic status based on income, education and employment history.

Conclusion
We identified several socioeconomic disparities that were more prevalent in children with severe (acute) asthma and demonstrated an unequal distribution of socioeconomic determinants in the Netherlands. Comprehensive assessment and mitigation of these determinants may improve health equity in paediatric severe asthma.

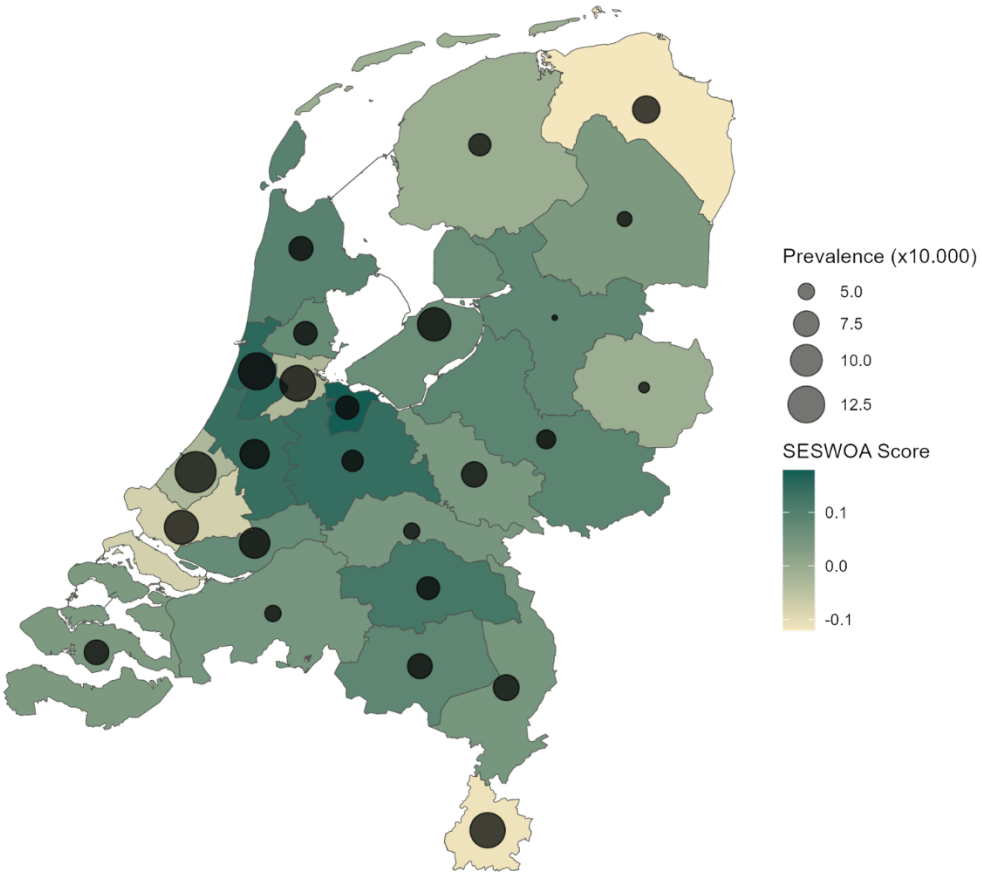

Figure 1: **Map of the Netherlands with the severe asthma prevalence and the SESWOA scores (Socioeconomic status, Neighbourhood and Environmental Analysis) per region in 2022**

The map of the Netherlands with the severe asthma prevalence as per 10.000 as well as the SESWOA-scores as a measure of socioeconomic status in children aged 6-17 years in 2022. There is a socioeconomic health gradient of paediatric severe asthma in the Netherlands. Generally, in regions with a low socioeconomic status, a high asthma prevalence is observed.

3.3 - Automatic Apnea Detection and Classification Using Machine learning and Transcutaneous Electromyography of the Diaphragm | Fabio Blom

Blom, F.A. (1,2), Hutten, G.J. (1,2), De Jongh, F.H.C (1,3), Van Kaam, A.H. (1,2), Van Leuteren, R.W. (1,2)

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(2) Amsterdam Reproduction and Development research institute, Amsterdam, The Netherlands.
(3) Faculty of Science and Technology, University of Twente, Enschede, The Netherlands.

Rationale
Apnea of prematurity in preterm infants has detrimental outcomes, and prevention and treatment is essential. However, current cardiorespiratory monitoring techniques lack accuracy. Transcutaneous electromyography of the diaphragm (dEMG) previously showed potential for detecting apnea events. We aimed to develop a real-time machine learning (ML) model capable of detecting and classifying apnea events using dEMG.

Methods
In this pilot study, preterm infants (gestational age 26-32 weeks) were measured for 4-8 hours to obtain diaphragm electrical activity (dEMG), airway pressure (AWP), and oxygen saturation (SpO2). Two clinical experts labelled signal periods as central (CA), obstructive (OA) or noise. The labelled (1) dEMG, (2) AWP, and (3) SpO_2 were used as ML model input and the ML model output was detected CA or OA in real-time. The data was split into training (60%), validation (20%), and test (20%) sets. Main outcome measures were sensitivity (Sens), positive predictive value (PPV) scores.

Results
Twenty-one infants (median postmenstrual age 30.1 weeks, weight 1,185g) were measured, contributing to 107.7 hours of data, with 237 CA and 856 OA labels. In the test set, the ML-model detected 53 CA events and 103 OA events. This resulted in Sens and PPV scores of 77% and 87% for CA events, and 74% and 62% for OA events.

Conclusion
Our ML model can detect and classify apnea events in preterm infants using dEMG and current clinical parameters. These findings represent an important step toward a future dEMG-based bedside tool.

3.4 - Parental Mental Health After Very Preterm Birth: Contributors up to Term-Equivalent Age | Kirsten Muller

Muller, K.S. (1,2,3,4,5), Meesters, N.J. (2), Van Oers, H.A. (1,3,4,6), Obermann-Borst, S.A. (7), Aarnoudse-Moens, C.S.H. (1,3,4,5), Tataranno, M.L. (8), Lopriore, E. (9), Raets, M.M.A. (10), Van Ganzewinkel, C.J. (11), Dijk, P.H. (12), Van den Akker, C.H.P. (3,13), De Boode, W.P. (14), Schuerman, F.A.B.A (15), Van Kaam, A.H. (3,13), Reiss, I.K.M. (2), Benders, M. (8), Simons, S.H.P. (2), Van den Bosch, G.E. (2), Haverman, L. (1,3,4,16), on behalf of the HIPPO study group

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(16) Amsterdam Public Health, Digital health, Amsterdam, The Netherlands

Rationale
Preterm birth and NICU admission are not only extremely stressful for the infant, but also for parents, impacting their mental health. Understanding key contributors to parental mental health is essential for prevention and targeted early interventions. This national multicenter prospective cohort study aimed to describe the development of parental mental health following preterm birth (<29 weeks of gestation), and identify contributing factors for mothers and fathers separately.

Methods
As part of the HIPPO study, parents completed questionnaires assessing posttraumatic stress and depressive symptoms 1–2 weeks after birth, 1 month after birth, and around term-equivalent age. Additional questionnaires captured prenatal psychosocial history, birth-related and family factors, postnatal stressors, and protective factors.

Results
Data from 217 families (259/446 children) were analyzed. Elevated posttraumatic stress symptoms were reported by 20.3–35.1% of mothers and 15.1–16.4% of fathers throughout time, while 39.4% of mothers and 19.3% of fathers reported elevated depressive symptoms 1–2 weeks after birth, and 27.2% vs. 24.3% experienced elevated symptoms up to term-equivalent age. For both parents, prenatal psychosocial history and environmental NICU stressors were significant contributors to parental mental health. More neonatal stress exposure, having fewer children and perceived social support were additional factors for fathers only.

Conclusion
These findings highlight the impact of preterm birth and NICU admission on parental mental health. Identification of shared and parent-specific risk factors is important to identify parents with the highest risk for adverse outcomes and provide interventions promptly. Further research should focus on prevention and early interventions.

3.5 - Functional power training increases calf muscle volume in children with spastic paresis | Babette Mooijekind

Mooijekind B (1,2,3), Bar-On L (2), van Vulpen L (4), Van den Broeck C (2), Jaspers RT (5), Weide (5), van der Krogt MM (1,3), Buizer AI (1,3,6)

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(4) Amsterdam Rehabilitation Research Center, Reade, Amsterdam, The Netherlands
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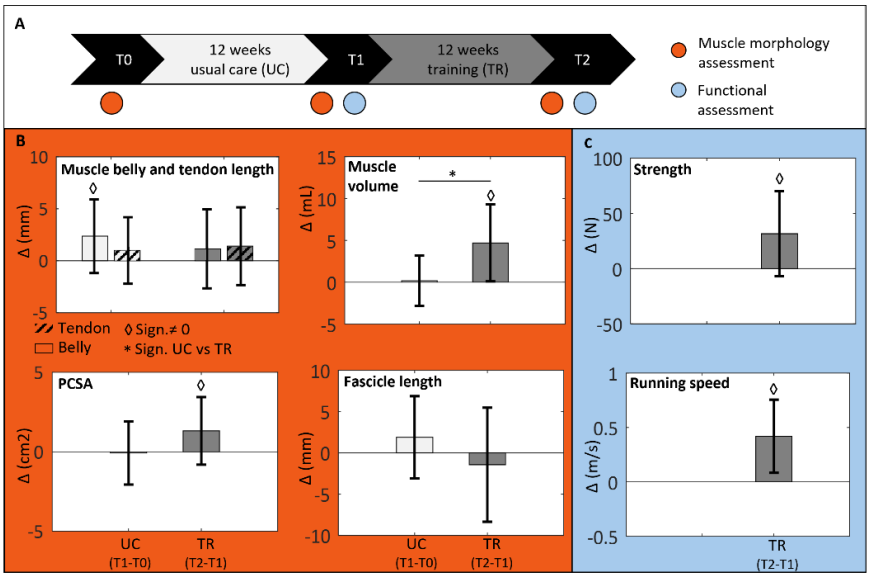
(6) Emma Children's Hospital, Amsterdam UMC, Amsterdam, The Netherlands

Rationale
Children with spastic paresis (SP) often experience muscle weakness and shortening, limiting walking capacity. Functional training improves walking and running capacity, but its effects on muscle morphology remain unclear. We investigated how training impacts gastrocnemius medialis (GM) morphology in children with SP. We hypothesized that GM volume and physiological cross-sectional area (PCSA) would increase, potentially lengthening the muscle belly due to the GM pennate structure.

Methods
Twenty-two ambulatory children with SP participated in a twelve-week functional power training program. In a double baseline study design, GM morphology, i.e. muscle belly, tendon, fascicle length, muscle volume, and PCSA (volume/fascicle length), was assessed twelve weeks before (T0), just before (T1), and after training completion (T2) using 3D ultrasound. Isometric GM strength and running speed were assessed at T1 and T2. Morphological changes between usual care (T1–T0), training (T2–T1), and isometric strength and running speed (T1 vs T2) were compared with paired t-tests.

Results
GM volume increased by 5.3±5.3mL after functional power training ($p<0.001$) compared to usual care. PCSA did not change between T0 and T1, but was 13% larger at T2 (10.4±4.8cm) compared to T1 (11.6±4.8cm). However, changes in PCSA or other GM length variables did not differ between usual care and training. After training, isometric plantar flexor strength increased by 19% and running speed by 15% (all $p<0.001$).

Conclusion
Functional power training increases GM volume, without altering GM length in children with spastic paresis. The increase in volume may contribute to the functional progress after functional power training.


A
T0
12 weeks
usual care (UC)
T1
12 weeks
training (TR)
T2
Muscle morphology
assessment
Functional
assessment
B
Muscle belly and tendon length
Δ (mm)
Tendon
Belly
◊ Sign.≠ 0
* Sign. UC vs TR
Muscle
volume
Δ (mL)
*
PCSA
Δ (cm2)
Fascicle length
Δ (mm)
UC
(T1-T0)
TR
(T2-T1)
C
Strength
Δ (N)
Running speed
Δ (m/s)
TR
(T2-T1)

3.6 - Antibiotics in the first week of life and the association with atopic diseases at ages 9-12: a prospective cohort study| Nora Carpaij

Carpay, N.C. (1,2), Kamphorst, K. (1,3), Vlieger, A.M. (2) & van Elburg, R.M. (1)

(1) Amsterdam UMC, University of Amsterdam, department of paediatrics, Amsterdam Gastroenterology and Metabolism Research Institute, Amsterdam Reproduction & Development
(2) Department of Paediatrics, St. Antonius Hospital, Utrecht, The Netherlands.
(3) Department of Paediatrics, Deventer Hospital, Deventer, The Netherlands.

Rationale
Dysbiosis in early life has been associated with the development of atopic diseases. In the INCA study, antibiotic treatment in the first week of life was associated with wheezing at one year, and food allergies at 4-6 years. This follow-up study investigates whether these associations persist at age 9-12, and whether new associations with other atopic diseases have developed.

Methods
The INCA cohort consisted of 436 children included in 2012-2015 to investigate the long-term effects of antibiotic treatment in the first week of life. Term born infants from four Dutch hospitals were included, of which 151 received intravenous antibiotics in their first week of life due to suspected early onset sepsis (AB+), and 285 were unexposed infants (AB-). In the 9-12 year follow-up study, parents and children filled out questionnaires on atopic diseases and general practitioner's diagnoses were collected.

Results
The follow-up questionnaire was completed by 314 participants (72%). Parental-reported and test-confirmed food allergies were more prevalent in AB+ children, compared to AB- (odds ratio (OR) 3.52, 95% confidence interval (CI) 1.50-8.251 and OR 6.6, 95% CI 1.3-32, respectively). However, no significant differences existed between AB+ and AB- in the incidence of asthma (OR 0.73, 95% CI 0.25-21) or inhalant allergies (OR 1.03, 95% CI 0.554-1.91). The "any allergy" diagnosis by general practitioners was more prevalent in AB+ than AB- (OR 3.0, 95% CI 1.2-7.6).

Conclusion
Antibiotic treatment in the first week of life is associated with food allergies at ages 9-12, but not with asthma, inhalant allergies or eczema.

3.7 - Gastrocnemius medialis muscle morphology and function after lengthening surgery in adolescents with cerebral palsy | Gaia van den Heuvel

Mooijekind, B.M. (1,2,3), Van den Heuvel, G. (1,3), Van der Krogt, M.M. (1,3,7), Witbreuk, M.M.E.H. (1,7), Schallig, W. (1,4), Jaspers, R.T. (3,5), Weide, G. (3,5), Bar-On, L. (2), Buizer, A.I. (1,3,7)

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(6) Vrije Universiteit Amsterdam, Faculty of Behavior and Movement Science.
(7) Emma Children's Hospital, Amsterdam UMC, Amsterdam, The Netherlands.

Rationale
Plantarflexion contracture is a common deformity in children with cerebral palsy (CP). Surgical gastrocsoleus aponeurotic lengthening can improve ankle range of motion (ROM). However, effects on muscle morphology are not yet known. We assessed the effects of gastrocsoleus lengthening on gastrocnemius medialis (GM) morphology and ankle ROM during gait in CP.

Methods
Eight individuals with spastic CP (12-19 years) were assessed before and one year after gastrocsoleus surgery. All had a 3D ultrasound of the GM, clinical examination, and 3D gait analysis. Outcomes were compared using Wilcoxon signed-rank tests.

Results
Results are shown in Figure 1. Post-operatively, tendon length increased by 11.4% [5.6:32.6%] (median [min:max]), p=.01), while fascicle length decreased by -14.2% [-44.7:-5.5%], p=.02. Pennation angle increased by 7.2° [0.1:14.6°], p=.02. Muscle volume did not change, but increased in 5/7 individuals. Physiological Cross-Sectional Area increased by 48.1% [8.8:96.8%], p=.03.

Ankle ROM during gait decreased in 7/8 individuals, by median 3.7° [-9.2:+14.2°], although not significant (p=.20). Although maximal active dorsiflexion (DF) increased by 4.8° [-8.9:+35.6°], p=.38, maximal active plantarflexion (PF) decreased by 8.0° [-21.5:+6.1°], p=.08. Maximum passive DF increased by 12.5° [+0:+55°], p=.02. Power absorption during early stance decreased by 0.92 [-0.0073:-1.46] Watt/kg, p=.02, but push-off power did not increase (0.14 [-0.41:+0.45] Watt/kg, p=.58).

Conclusion
Despite inter-individual variation, gastrocsoleus lengthening increases passive ankle dorsiflexion by elongating the Achilles tendon, while fascicles shorten and PCSA increases. Power absorption during early stance decreases, but no overall effect on push-off power was shown. The reduction in maximal plantarflexion during gait could be related to the shorter fascicles.

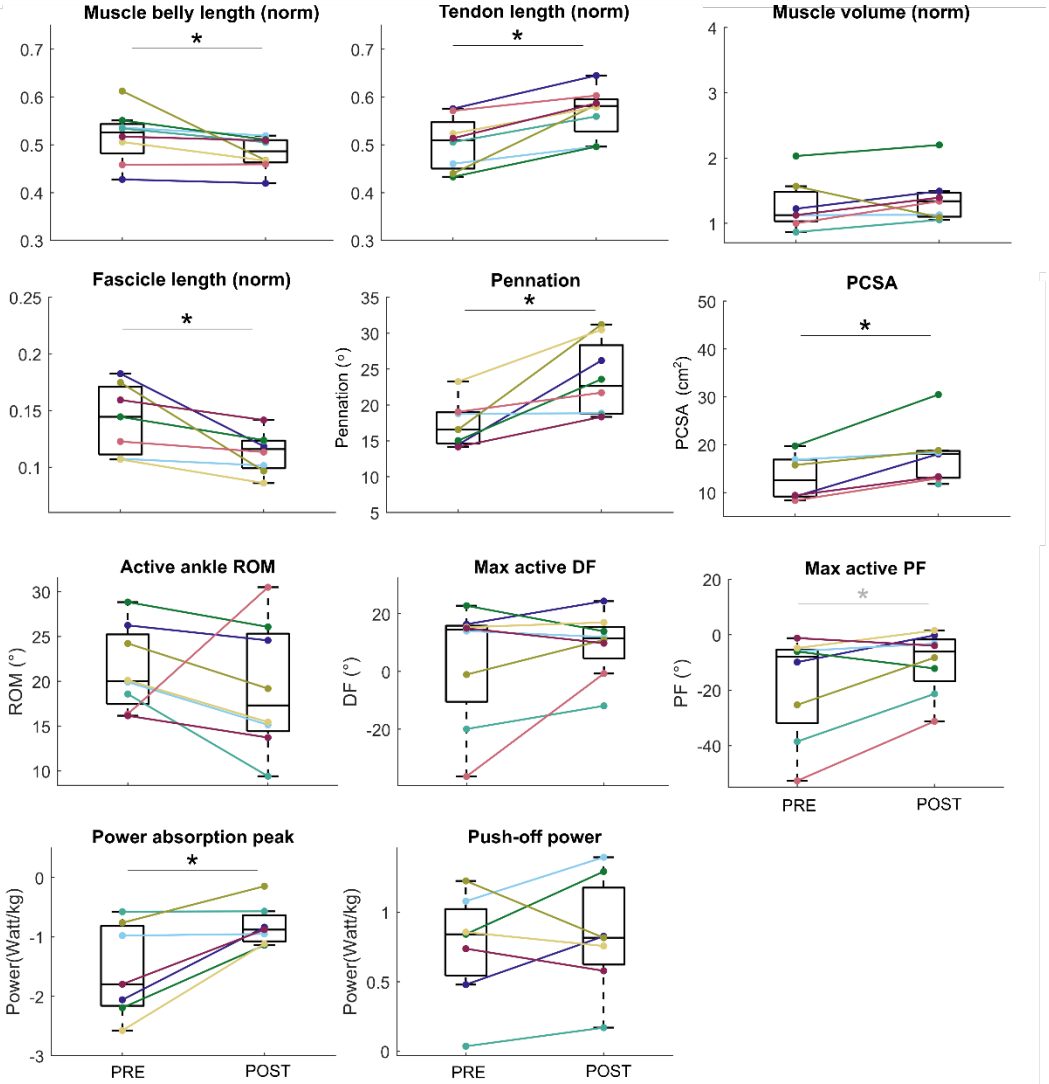


Figure 1. GM morphology and ankle function before (PRE) and after surgery (POST) (color coded per individual). * = significance; in black p<0.05 (significant); in grey p<0.1 (trend).

3.8 - The effect of antenatal paracetamol on breathing effort of premature infants at birth: A pilot trial | Timothy Panneflek

Panneflek, T.J.R. (1), Dekker, J. (1), Kuypers K.L.A.M., (1), Derleth, D.P. (2), Polglase, G.R. (3,4), van der Meeren, L. (5,6), Wind, M. (7), Visser, R. (1), Hooper, S.B. (3,4), van den Akker, T. (7), te Pas, A.B. (1)

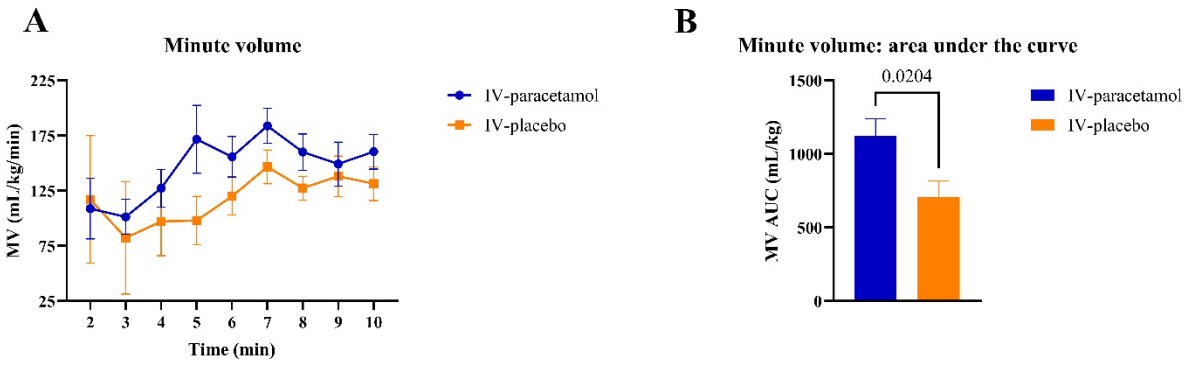
(1) Division of Neonatology, Department of Paediatrics, Willem-Alexander Children's Hospital, Leiden University Medical Centre, Leiden, the Netherlands
(2) Department of Paediatric and Adolescent Medicine, Mayo Clinic College of Medicine, Rochester, MN.
(3) The Ritchie Centre, Hudson Institute of Medical Research, Melbourne, Victoria, Australia
(4) Department of Obstetrics and Gynaecology, Monash University, Melbourne, Victoria, Australia
(5) Department of Pathology, Leiden University Medical Centre, Leiden, the Netherlands.
(6) Department of Pathology, Erasmus MC, University Medical Centre Rotterdam, the Netherlands.
(7) Department of Obstetrics, Leiden University Medical Centre, Leiden, the Netherlands.

Rationale
Prostaglandin E2 (PGE2) is known to suppress perinatal breathing. Lowering antenatal PGE2 concentrations with paracetamol could stimulate spontaneous breathing in premature infants at birth. We aimed to investigate feasibility and effect of antenatal paracetamol administration.

Methods
In a randomised, placebo-controlled, triple-blind pilot trial, pregnant women <31 weeks' gestation were randomised to receive intravenous paracetamol (intervention) or placebo (control). Primary outcome was feasibility of administering study medication within 30-120 minutes prior to birth. Secondary outcomes comprised breathing and additional physiological parameters of the premature infants in the first 1-10 minutes after birth. Planned enrolment was 40 pregnant women.

Results
The trial was halted after enrolling 23 women due to a low inclusion rate. Of the 23 women, 18 received study medication; nine in the intervention group and nine in the control group. Eleven (48%) women received study medication within the specified time.
In infants, minute volume was not significantly different between groups (intervention group (n=13) vs control group (n=12); mean±SEM; 147±12 vs 114±14 mL/kg/min, p=0.093). The intervention group had significantly higher area under the curve for minute volume, inspiratory drive, and heart rate (1120±410 vs 707±346 mL/kg, p=0.020; 11.8±1.0 vs 8.4±1.3 mL/kg/breath/s, p=0.046; 137±5 vs 121±5 beats/min, p=0.037).

Conclusion
Antenatal paracetamol administration 30-120 minutes prior to birth was only feasible in half of the women, but when given, breathing effort of premature infants may improve.



3.9 - Rationale for improving school toilet facilities in the Netherlands | Anne ter Schure

Anne C. ter Schure (1,4,5), Sophia P. van Streun (1,2,4,5), Marianne Rook (7) , Bart Sandberg (6), Joep P.M. Derikx (1,4,5), Lodewijk W.E. van Heurn (1,4,5), , Marc A. Benninga (3) , Ilan J.N. Koppen (3), Mariël C.H. Croon (7), Ramon R. Gorter (1,4,5)

(1) Department of Pediatric Surgery, Amsterdam UMC location University of Amsterdam, Amsterdam, Noord-Holland, The Netherlands. (S.P. van Streun MD, A.C. ter Schure MD, J.P.M. Derikx prof., L.W.E. van Heurn prof., R.R. Gorter PhD)
(2) Department of Pediatric Gastroenterology and Nutrition, Follow Me program, Amsterdam UMC location University of Amsterdam, Amsterdam, Noord-Holland, The Netherlands. (S.P. van Streun MD)
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(4) Amsterdam Gastroenterology Endocrinology and Metabolism Research Institute, Amsterdam, Noord-Holland, The Netherlands (S.P.M. van Streun MD, A.C. ter Schure MD, J.P.M. Derikx prof, L.W.E. van Heurn prof, R.R. Gorter PhD)
(5) Amsterdam Reproduction and Development Research Institute, Amsterdam, Noord-Holland, The Netherlands (S.P.M. van Streun MD, A.C. ter Schure MD, J.P.M. Derikx prof, L.W.E. van Heurn prof, R.R. Gorter PhD)
(6) Verian, Amsterdam, Noord-Holland, The Netherlands (B. Sandberg MSc)
(7) Dutch Digestive Health Fund, Amersfoort, Utrecht, the Netherlands. (M. Rook MSc, M.C.H. Croon MSc)

Rationale
This study aimed to assess the prevalence of toilet avoidance and withholding stool at school. Secondary, it explored the differences of withholding behavior by sex and geographic location of the school, identifies reasons for withholding, and describes physical symptoms and healthcare utilization in a large nationwide cohort in the Netherlands.

Methods
In this cross-sectional study, we used an online questionnaire developed by experts of the Amsterdam UMC and the Dutch Digestive Health Fund. An external research agency recruited children from a nationwide online panel in the Netherlands. Children from primary schools (aged 8-12) and high schools (aged 13-16) were included for the questionnaire on toilet behavior at school.

Results
In July 2024, a total of 1,000 children completed the questionnaire: 518 aged 8–12 years and 482 aged 13–16 years. Withholding stool was reported by 34% of the primary school group and 63% of the high school group, with no significant sex and geographic differences. Hygiene and privacy concerns were the most commonly cited reasons for withholding stool. Overall, 41% rated school toilet cleanliness as insufficient. Abdominal pain, nausea symptoms were frequently reported, including involuntary stool loss in 5%. Up to 13% had visited a physician for symptoms due to withholding.

Conclusion
Children in both primary and high school frequently avoid school toilets, primarily due to hygiene and privacy concerns. Improving toilet facilities may reduce toilet avoidance, and thus, withholding stool, fecal incontinence, gastrointestinal symptoms, and related physician visits. Addressing these issues is essential to support children's physical, psychological and educational well-being.

SLAM session II abstracts

4. Mary Dresselhuys zaal

14:00 - 15:20

Gesponsord door *Pfizer*

	Abstract titel	Auteur
4.1	Pfizer	
4.2	Triglycerides as risk factor for thrombosis in neonates	*Samier Rahimi*
4.3	Indoor mold exposure and asthma in children: a literature study	*Ravi Goes*
4.4	Faecal leucine profiles can differentiate paediatric inflammatory bowel disease from irritable bowel syndrome and functional abdominal pain.	*Lana Verstoep*
4.5	Effectiveness of vaping interventions in young people: a systematic review	*Marit Erbrink*
4.6	Effect of red blood cell transfusion on inflammatory and angiogenic pathways in patients with sickle cell disease	*Lydian de Ligt*
4.7	Barriers and facilitators of physical activity in congenital heart disease: The healthcare professional's perspective	*Rebecca Meuldijk*
4.8	TTV-loads in pediatric kidney transplantation: association with immunosuppression, HLA mismatch, age and sex	*Luna Klomp*
4.9	Neurocognitive outcomes in toddlers with Sickle Cell Disease	*Noa IJdo*

4.1 – Pfizer

Opening of the SLAM session will be provided by Pfizer

4.2 - Triglycerides as risk factor for thrombosis in neonates | Samier Rahimi

Rahimi S, Verweij MW, Weissenbruch MM, Klaassen ILM

Amsterdam UMC location AMC, Emma Children's Hospital, Department of Pediatric Infectious Diseases and Immunology, Amsterdam, The Netherlands.

Rationale
Venous thromboembolism (VTE) is a rare but serious complication in neonates. While risk factors such as central venous catheters (CVCs), sepsis, and prematurity have been well studied, the contribution hypertriglyceridemia remains underexplored. Elevated triglyceride levels have been associated with thrombosis in adults, but their role in neonatal thrombosis is unclear. This study aims to investigate the association between serum triglyceride levels and the risk of thrombosis in neonates admitted to the NICU.

Methods
A retrospective case-control study was conducted at the Emma Children's Hospital, Amsterdam UMC, including neonates admitted between October 2015 and 2021. The study population comprised 110 neonates with confirmed VTE and 60 neonates without VTE who had available triglyceride measurements. Data on demographics, clinical parameters, laboratory results, and imaging were collected. Hypertriglyceridemia was defined as serum triglyceride levels >2.00 mmol/L. Univariable and multivariable logistic regression analyses assed associations between triglyceride levels and VTE, adjusting for confounders.

Results
Neonates with thrombosis were more often male (66.5% vs. 43.3%, p=0.005) and had a higher comorbidities rates. Hypertriglyceridemia was more prevalent in the VTE group (51.8% vs. 8.3%, $p < 0.001$). Elevated triglycerides were strongly associated with thrombosis (OR 11.62; 95% CI 4.31–31.24). After adjusting for confounders, this association remained significant (OR 6.53; 95% CI 1.37–31.23).

Conclusion
Elevated triglyceride levels are significantly associated with VTE in neonates, suggesting hypertriglyceridemia may contribute to a prothrombotic state. Male sex was also identified as an independent risk factor. Monitoring triglyceride levels may help identify neonates at risk for thrombosis, supporting early, low-threshold anticoagulant therapy.

4.3 - Indoor mold exposure and asthma in children: a literature study | Ravi Goes

Goes, R.M.K. (1), van den Berg, S (1,2), Hussain, T. (3), Hashimoto, S.H. (1,2), Chan, C. (4), Terheggen-Lagro S.W.J. (3), Kapitein, B. (2) & Vijverberg, S.J.H. (1,3)

(1) Amsterdam UMC location VUMC, Department of Pulmonary Medicine, Amsterdam, The Netherlands.
(2) Amsterdam UMC location AMC, Emma Children's Hospital, Paediatric Intensive Care Unit, Amsterdam, The Netherlands
(3) Amsterdam UMC location AMC, Emma Children's Hospital, Department of Pediatric Pulmonology and Allergy, Amsterdam, The Netherlands.
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Rationale
Indoor mold exposure has been linked with the onset of childhood asthma, but the strength and consistency of this relation remains unclear. This review aims to provide an overview of the most recent literature assessing the association between indoor mold exposure and asthma in children.

Methods
This review used a systematic literature search, conducted in PubMed for studies published between September 2020 and September 2025. Studies were included if they assessed the relationship between indoor mold exposure (exposure) and asthma onset or asthma symptoms (as outcomes) in children. Critical appraisal was performed using the checklists from the Joanna Briggs Institution (JBI).

Results
In total, 449 articles were identified of which 13 studies met all the inclusion criteria. These studies included cross sectional (n=10), case control (n=1) and cohort study designs (n=2). Studies were performed in Asia (n = 7), Europe (n = 4) and the USA (n = 2). Ten studies focused on asthma prevalence in children and five studies included measures of asthma severity. Nine out of ten studies observed a positive association between mold exposure and asthma prevalence, with Odds Ratios ranging between 1.01 to 3.52. Furthermore, mold exposure was associated with poorer asthma control, increased wheezing and more asthma-related health care visits, with all studies reporting statistically significant associations.

Conclusion
There is a consistent trend that indoor mold exposure increases the risk of the onset of asthma as well as more uncontrolled asthma in children. Studies in the Dutch setting are lacking.

4.4 - Faecal leucine profiles can differentiate paediatric inflammatory bowel disease from irritable bowel syndrome and functional abdominal pain | Lana Verstoep

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Rationale
Inflammatory bowel disease (IBD) is a chronic inflammatory disorder of the gastrointestinal tract. Diagnosing IBD involves clinical symptoms, along with laboratory, radiologic, endoscopic, and histologic findings to differentiate IBD from other conditions. Previous research have shown faecal amino acids, particularly leucine, can distinguish IBD from controls.

Methods
Faecal samples were selected from a cross sectional study at the Emma Children's Hospital, including treatment naïve IBD and patients with Irritable Bowel Syndrome (IBS) and Functional Abdominal Pain-Not Otherwise Specified (FAP-NOS) fulfilling the Rome IV criteria. Targeted liquid chromatography-mass spectrometry (LC-MS) was used to measure amino acid concentrations, focusing on leucine and the leucine/isoleucine ratio.

Results
In total 106 patients were included, of whom 48 newly diagnosed IBD and 20 patients with FAP-NOS, 20 with IBS-Constipation, 9 with IBS-Mixed and 9 with IBS-Diarrhoea. Absolute faecal leucine concentrations were significantly higher in IBD compared to IBS/FAP-NOS controls (p value= 1.04E-4, FDR= 1.38E-4). The leucine/isoleucine differed significantly between IBD and controls (p value= 3.50E-6, FDR= 7.00E-6, with an AUC of 0.75 (0.65-0.84) with an cut-off value of 1.44. Within the control group, absolute leucine (p= 0.01, FDR= 0.02) and isoleucine (p value= 0.001, FDR= 0.006) concentrations in IBS-M and IBS-D resembled IBD levels more closely than IBS-C and FAP-NOS, while the ratio did not differ between different control diagnosis.

Conclusion
The faecal leucine/isoleucine ratio outperforms absolute leucine concentration in differentiating paediatric IBD from IBS and FAP-NOS. Furthermore, significant differences in absolute leucine and isoleucine concentrations were found within IBS subgroups, indicating possible underlying differences in pathophysiological mechanisms.

4.5 - Effectiveness of vaping interventions in young people: a systematic review | Marit Erbrink

Erbrink, M. (1,2), van den Berg, S. (1,3), Hussain, T (2), Hashimoto, S.H. (1,2), S.W.J. Terheggen-Lagro, S.W.J. (2), Kapitein, B (3) & Vijverberg, S.J.H. (1,2)

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Rationale
Vaping among adolescents has become a growing public health concern due to the long-term health risks. 1 in 4 Dutch adolescents have experience with vaping. It remains unclear which interventions are most effective for vaping prevention or cessation in adolescents and young adults.

Methods
A systemic review was undertaken in PubMed, MEDLINE. Articles were included if it addressed studies focusing on interventions to prevent or cease vaping and smoking in adolescents and (young) adults. Outcomes of interest were: vaping cessation, intentions to start vaping and vaping abstinence. Only clinical trials and randomized controlled trials (RCT) were included.

Results
In total, 73 articles were identified, and after screening 20 articles were included. 11 articles focused on adolescents, while 9 on (young) adults. The majority of the studies was performed in the USA, none in the Netherlands. Studies show that structured social media programs can both prevent and cease smoking in adolescents. Primary school based prevention programs demonstrate effectiveness in a longer term, especially when combined with follow-up programs. For cessation, targeted text messages show the ability to improve vaping abstinence in adolescents and young adults at a relative short term (7 months).

Conclusion
School prevention programs and targeted text message programs seem to be effective tools to prevent and or cease vaping in adolescents, however research in the Dutch context is lacking.

4.6 - Effect of red blood cell transfusion on inflammatory and angiogenic pathways in patients with sickle cell disease | Lydian de Ligt

de Ligt, L.A. (1,2,3), Thakoerdin, S.R. (2), Zwolsman, M. (1,2), Stegemann, G. (1), Matlung, H. (1), Kuijpers, T.W. (1,4), Biemond, B.J. (2), Fijnvandraat, K. (3), van Bruggen, R. (1), Nur, E. (1,2)

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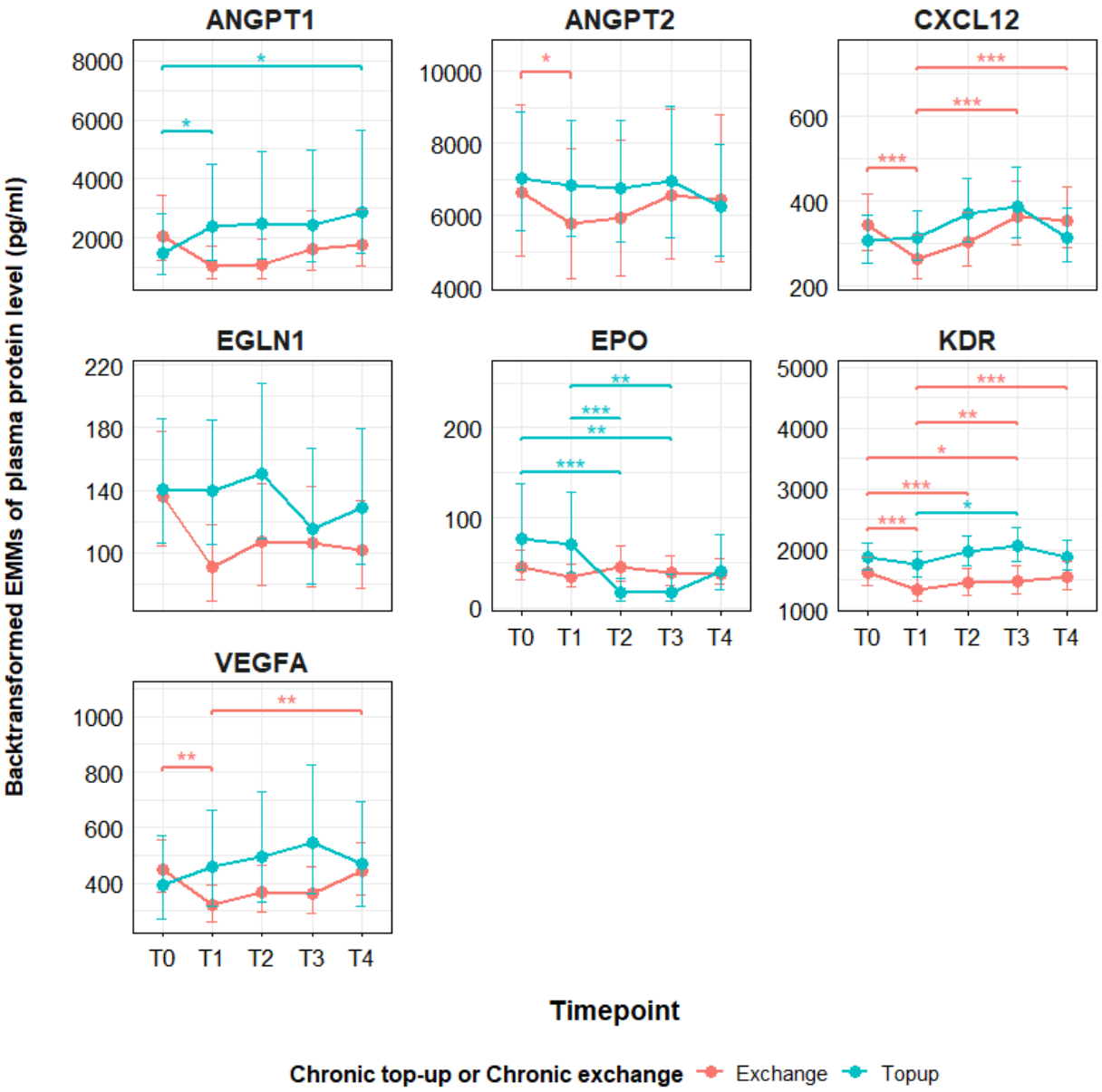
Rationale
Sickle cell disease (SCD) is a chronic inflammatory state, characterized by increased plasma levels of inflammatory and angiogenic proteins. Although red blood cell (RBC) transfusion is known to have immunomodulatory effects in other conditions, its potential effects on the inflammatory state in SCD remain largely unknown. This study aimed to explore the longitudinal effects of RBC transfusion on plasma inflammatory and angiogenic proteins in chronically transfused patients with SCD.

Methods
Plasma samples were collected from SCD patients treated with RBC transfusion, directly pre-transfusion and 1 hour, 24-72 hours, 1 week and 2 weeks post-transfusion. Proximity Extension Assay (PEA) technology was used to measure plasma levels of 21 proteins at each of these timepoints.

Results
Twenty-four patients (median age 26 years (IQR: 13 - 39)) treated with either chronic exchange transfusion (N=12) or chronic top-up transfusion (N=12) were included in the study. Exchange transfusion resulted in decreased levels of proteins released during inflammasome activation (IL-1β, IL-18), B cell survival and activation (TNFRSF13B/TACI, TNFRSF13C/BAFFR, TNFSF13/APRIL), angiogenesis (ANGPT2, VEGFA, KDR, CXCL12), and neutrophil differentiation, recruitment and activation (G-CSF, G-CSFR, CXCL1, CXCL5, CXCL6), at 1 hour post-transfusion, returning gradually to pre-transfusion values during 2 weeks post-transfusion. In contrast, top-up transfusion resulted in moderate changes with decreased levels of EPO and increased levels of ANGPT1.

Conclusion
While exchange transfusion seems to temporarily reduce the activation of pro-inflammatory and pro-angiogenic pathways, top-up transfusion might result in reduced hypoxia and increased vascular stability. These results enhance our understanding of the effects of RBC transfusion on inflammatory and angiogenic pathways.

Figure 1 Changes in protein levels involved in angiogenesis before and after top-up or exchange transfusion
T0 = directly pre-transfusion; T1= 1 hour post-transfusion; T2 = 24-72 hours post-transfusion; T3 = 1 week post-transfusion; T4 = 2 weeks post-transfusion. Abbreviations: Angiopoietin-1 (ANGPT1); Angiopoietin-2 (ANGPT2); Egl nine homolog 1 (EGLN1); Erythropoietin (EPO); Vascular endothelial growth factor receptor 2 (KDR, VEGFR2); Vascular endothelial growth factor (VEGFA); Stromal cell-derived factor 1 (SDF1, CXCL12). The levels of ANGPT1, ANGPT2, CXCL12, EGLN1, KDR and VEGFA are expressed in picograms per milliliter (pg/ml). The level of EPO is expressed in milliunits per milliliter (mU/mL).



4.7 - Barriers and facilitators of physical activity in congenital heart disease: The healthcare professional's perspective | Rebecca Meuldijk

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Rationale
Sufficient physical activity (PA) is crucial for a healthy physical, psychological, social and cognitive development. In children with CHD, PA lowers the risk of later complications and is related to quality of life. Yet, PA levels among this population are insufficient. Consensus statements have emphasized the role of healthcare professionals (HPs) in PA promotion. As such, insights into HPs' experiences are needed to improve care. This study aims to investigate HPs' experience with and perspective on barriers and facilitators leading to low levels of PA in children with CHD.

Methods
HPs working in six Dutch university medical centers were interviewed using semi-structured interviews (N = 21). Themes and questions were outlined beforehand, focusing on barriers, facilitators and communication about PA and CHD. Interviews were recorded and transcribed. Data analysis will be done using thematic reflexive analysis and findings will be applied to the COM-B model of behaviour change. Preliminary results are outlined.

Results
HPs describe children with CHD as generally insufficiently active, though major individual differences exist. Most children do not have physical restrictions that withhold them to exercise. Participation in PA seems more dependent on other factors. Perceived barriers and facilitators to sports and PA are child- and family-related (e.g., motivation, anxiety, family activities), social (e.g., lack of awareness in social environment, cultural norms, encouragement from teachers) and environmental factors (e.g., healthcare system, community sports days).

Conclusion
PA in children with CHD is insufficient. A complex interplay of factors determines PA levels in CHD. New PA interventions should intervene on this interplay.

4.8 - TTV-loads in pediatric kidney transplantation: association with immunosuppression, HLA mismatch, age and sex | Luna Klomp

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Rationale
Kidney transplantation (KTx) is the treatment of choice for children with end-stage renal disease. Lifelong immunosuppressive therapy prevents graft rejection, but balancing efficacy and toxicity remains challenging. Current dosing strategies based on plasma drug levels do not accurately reflect immune competence. Torque Teno virus (TTV) load has emerged as a biomarker of immune activity in adult KTx recipients, with higher loads indicate reduced immunity. This study investigates post-transplant TTV load in pediatric KTx recipients and its association with age, sex, immunosuppressive regimen, and HLA mismatch.

Methods
TTV DNA in serum/plasma of 92 children (median age = 10.5 years) was quantified by qPCR before and up to two years post-transplant (first year: every 2 months; second year: every 4 months). Statistical analyses were performed in R.

Results
All patients were TTV positive. Median pre-KTx load was 3.39 Log10 copies/mL, peaking at 7.72 Log10 at 4 months and stabilizing at 5.90 Log10 after 14 months. No correlations with age or sex were found ($p=0.638$; $p=0.35$). TTV load decreased significantly over time post-KTx ($p=0.0017$) and was unaffected by immunosuppressive regimen ($p=0.446$). Significant differences were observed between HLA-mismatch groups ($p<0.05$).

Conclusion
Post-KTx, TTV loads increased, peaking at 4 months and stabilizing by 14 months, with an overall decline over time. No associations were found with age, sex, or immunosuppressive regimen. TTV load differed significantly by HLA mismatch, being higher with more mismatches. These findings support TTV as a potential biomarker for immune monitoring after pediatric kidney transplantation. Future analyses will assess correlations with immunosuppressive drug levels and aim to define clinically relevant cut-off levels.

4.9 - Neurocognitive outcomes in toddlers with Sickle Cell Disease | Noa IJdo

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Rationale
Sickle cell disease (SCD) is a genetic disorder that transforms red blood cells into a sickle shape, leading to severe lifelong complications. Children with SCD face the risk of disrupted neurodevelopmental outcome through cerebral infarctions, anaemia, and inflammation. Neurocognitive functioning is crucial for social, behavioural and academic development, as well as later quality of life. However, standardized assessments are often confounded by motor and language development. Therefore, this study aims to investigate early neurocognitive functioning in infants with SCD using eye-tracking and to explore early determinants and the relationship with adaptive functioning.

Methods
This prospective observational study, employing an accelerated longitudinal design, assessed neurocognitive functioning in children with SCD and healthy peers aged between 6 and 24 months. Eye-tracking, an objective non-invasive method, was used to measure aspects of oculomotor control, information processing, and attention. At 24 months, the Bayley Scale of Infant Development (BSID-III) and the Strengths and Difficulties Questionnaire (SDQ) were administered. Testing was conducted during home environment visits using the mobile laboratory 'Emma Brain Bus'. Statistical analyses will be performed using generalized estimation equations.

Results
A total of 34 children with SCD and 58 healthy controls participated in the study. Results of the 24-month assessments will be presented, including group differences, correlates with clinical SCD characteristics and relations to the BSID.

Conclusion
The results may contribute to our knowledge of early neurocognitive impairment in SCD and support early identification of children at risk of impairment, enabling timely interventions to dampen the detrimental effects of SCD on the developing brain.

5. MARNIX FOYER

14:00 - 15:20

	Abstract titel	Auteur
5.1	Bronchodilator response is linked with uncontrolled moderate-to-severe childhood asthma and elevated IL-4 and IL-13	*Nariman Kotb Abbas Metwally*
5.2	Discussing parenthood and child mental well-being in adult mental health services: barriers and facilitators according to parents and professionals	*Rachel van Grootheest*
5.3	Use of stem cell-derived neural systems to elucidate the effect of antivirals on clinical and lab-adapted CMV	*Renata Vieira de Sa*
5.4	Interprofessional team meetings in the Jeroen Pit Huis: satisfaction about perceived content in parents and healthcare professionals	*Franka Roest*
5.5	Molecular Culture for diagnosing early onset neonatal sepsis: preliminary results of the EOS-CHAMPIONS study	*Jip Groen*
5.6	Neurodevelopment at 9 years of age in moderate and late preterm infants	*Lorijn de Kraker*
5.7	Effect of human milk processing in preventing CMV infection in complex human fetal intestinal mucosa organoids	*Eline Freeze*
5.8	Oxygen saturation thresholds in children with acute respiratory distress (OxyKids): a multicentre, open, parallel-group, randomised clinical trial	*Sam Louman-Slot*
5.9	Efficacy and Safety of Non-Pharmacological Treatments for Paediatric Functional Constipation: A systematic review and meta-analysis	*Anna de Geus*

5.1 - Bronchodilator response is linked with uncontrolled moderate-to-severe childhood asthma and elevated IL-4 and IL-13 | Nariman Kotb Abbas Metwally

Nariman K A Metwally1,2,3,4,5, Simone Hashimoto1,2,3,4, Susanne J H Vijverberg1,2,3, Anne H Neerincx1, Barbara S Dierdorp2,6, Tamara Dekker2,6, Eric G Haarman4, Jan Willem Duitman1,2,6, Mario Gorenjak7, Antoaneta A Toncheva8, Susanne Harner8, Susanne Brandstetter9, Christine Wolff9, Paula Corcuera-Elosegui10, Leyre López-Fernández10, Olaia Sardón-Prado10,11, Maria Pino-Yanes12,13,14, Uroš Potočnik7,15,16, Michael Kabesch8,9, Aletta D Kraneveld17, René Lutter1,2,6, Suzanne W J Terheggen-Lagro4, Mahmoud I Abdel-Aziz1,2,3,18, Anke H Maitland-van der Zee1,2,3,4,18; on behalf of the SysPharmPediA Consortium

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Rationale
Bronchodilator response (BDR) is a key clinical feature in childhood asthma, but its relation to asthma pathophysiology is not fully understood. This study examines the associations between BDR, disease control and serum cytokines/chemokines in children with moderate-to-severe asthma (MSA).

Methods
BDR was assessed in 140 children (aged 6–17 years, 41% females) from the SysPharmPediA cohort using primarily the ERS/ATS 2022 guidelines (ΔFEV_1 >10% predicted) post-bronchodilator. Risk of uncontrolled asthma in relation to BDR was estimated by logistic regression model, adjusting for baseline lung function, age, sex, BMI z-score ethnicity, country, season, GINA step, and smoking exposure. Serum levels of 39 proteins were measured using Luminex Multiplex Assay; proteins with <40% missing values and below the limit of detection (LOD) were imputed by LOD/√2. Children with high and low BDR were compared for serum proteins by linear regression model, adjusting for covariates and applying false discovery rate correction.

Results
Children with high BDR (21%) had significantly higher odds of uncontrolled asthma (adjusted OR ≈ 3.22, 95% CIs: 1.07–11.3) and more frequent severe exacerbations in the past year compared with those with low BDR (70% vs 46%, P<0.05). High BDR children also showed significantly elevated serum levels of IL-13, IL-4, TNF-α, IL-6, IL-7, IL-8, IL-1β, and MMP-1 ($q < 0.05$).

Conclusion
In children with MSA, a high BDR is independently associated with poorer asthma control and a distinct inflammatory profile involving both T2 and non-T2 cytokines. BDR may serve as a marker for personalized asthma phenotyping.

5.2 - Discussing parenthood and child mental well-being in adult mental health services: barriers and facilitators according to parents and professionals | Rachel van Grootheest

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Rationale
Children of parents with mental illness (COPMI) have a higher chance of developing psychological problems themselves (1). However, these children tend to be overlooked by adult mental health services (AMHS) and parenthood and child mental well-being are seldom discussed in AMHS (2). This is a missed opportunity for prevention.

Methods
Focus groups with parents with their own experience in AMHS (N = 10) and with professionals in AMHS (N = 10) were held to gain insight into facilitating and inhibiting factors for discussing parenthood and child well-being in AMHS.

Results
Both parents and professionals mentioned fear as an inhibiting factor. Parents are afraid that their child will be taken away if they speak openly about their struggles in parenthood, while professionals are worried about damaging their therapeutic relationship with the parent. Examples of factors that can facilitate the discussion according to parents are making them feel seen and respected (e.g., by emphasizing their strengths) and offering suitable support for the children. According to professionals, examples of facilitating factors are increasing their knowledge (e.g., about signs of child-wellbeing), psychoeducation for parents (e.g., about intergenerational patterns) and facilitation by their organization (e.g., collaboration between child and adolescent mental health services and AMHS).

Conclusion
Working on the facilitating factors can lead to more conversations about parenthood and child well-being in AMHS as well as ensure that COPMI receive the help and support they need. We have used these insights in a pilot implementing this practice in AMHS.

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5.3 - Use of stem cell-derived neural systems to elucidate the effect of antivirals on clinical and lab-adapted CMV | Renata Vieira de Sa

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Rationale
Congenital cytomegalovirus (cCMV) infection remains a leading cause of neurological impairment in newborns, yet current treatment options are limited to postnatal administration of ganciclovir. Preclinical studies are hindered by the lack of physiologically relevant models and the predominant use of lab-adapted CMV strains with reduced clinical translatability. The use of human pediatric stem cell –derived neural models provide great opportunities to investigate CMV pathology and therapeuric interventions in vitro. In this study we investigated the safety and efficacy of FDA-approved antivirals—letermovir, ganciclovir, and maribavir—using 2D and 3D human induced pluripotent stem cell (iPSC)-derived neuronal models infected with either a circulating clinical isolate or a lab-adapted strain.

Methods
Two iPSC lines were differentiated into 2D neural progenitor cells (NPCs) and 3D regionalized neural organoids (RNOs). Cultures were infected with clinical or lab-adapted CMV and treated with clinically relevant concentrations of letermovir, ganciclovir, or maribavir for up to 24 days. Antiviral toxicity and efficacy were assessed via ATP-based viability assays and qPCR-based viral DNA quantification. Gene expression profiling of neurodevelopmental markers (SOX2, PAX6, CTIP2, SATB2), inflammatory markers (IL-6), and differentiation regulators (PPAR-γ) was conducted to evaluate infection and treatment impact.

Results
Both CMV strains replicated in NPCs and RNOs, but the clinical isolate caused significantly greater cytopathic effects and impaired expression of neurodevelopmental genes. Letermovir and ganciclovir reduced CMV copy numbers without exacerbating cytotoxicity, whereas maribavir had limited efficacy. In RNOs, the clinical isolate, but not the lab adapted, led to reduced cell viability and changes in gene expression. These changes in genes expression were rescued by treatment with letermovir and ganciclovir. Gene expression changes were more pronounced in clinical strain infections and were not observed in lab-adapted CMV-infected cultures, highlighting strain-specific pathogenicity.

Conclusion
Letermovir and ganciclovir showed antiviral efficacy in reducing viral load and restoring neural gene expression in CMV653941-infected models, with ganciclovir demonstrating a better safety profile in organoids. The finding of strain-specific pathogenicity supports the incorporation of clinically relevant models and virus strains into antiviral screening pipelines to improve translational relevance. This study emphasizes the importance of using human iPSC-derived in vitro models to better understand cCMV pathogenesis, evaluate therapeutic strategies and support clinical developments.

5.4 - Interprofessional team meetings in the Jeroen Pit Huis: satisfaction about perceived content in parents and healthcare professionals | Franka Roest

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Rationale
In Amsterdam, an innovative transitional care unit (TCU) has been developed: the Jeroen Pit Huis (JPH). Here, families of children with medical complexity (CMC) stay in homelike apartments with 24/7 supervision of healthcare professionals (HCP). In the TCU, HCP and parents evaluate transition goals in standardised phases during interprofessional team meetings (IPTMs). The aim of this study is to gain insight in 1) the themes discussed during an IPTM, 2) the perceived time allocation and satisfaction of parents and HCP with the IPTM.

Methods
This study employs a mixed method design. IPTMs are recorded, transcribed, and analyzed thematically using inductive and deductive approaches. Ten percent of the interviews will be analyzed by a second researcher. After each IPTM a survey on perceived time allocation and satisfaction is completed among attendees.

Results
So far, 37 IPTMs have been observed. A median of 6.0 HCP were present during IPTMs. Attendees included a nurse (100%), a family counsellor (100%), a physician (pediatrician 91,7% or resident 83,3%), and often the teamleader (77,8%). External HCPs (e.g., nephrologists) and parents attended less frequently, being present in 16.7% and 58.3% of meetings, respectively.
At the beginning of the stay, the theme 'disease management' is predominantly addressed, which gradually shifts towards 'parental confidence' as families approach discharge.
In the questionnaire, attendees report that the transition goals 'housing' and 'where to seek help' are discussed the least (respectively: median=1.0, range=4.0-1.0; median=1.0, range=1.0-5.0; 6-point scale).
Attendees are satisfied (combined median=4.9, range=1.0-6.0, 6-point scale) with the content of the themes discussed. Complete results will be presented at AKS.

Conclusion
Our findings show that attendees are satisfied with the content of themes discussed in IPTMs. Further analysis of IPTM content and team composition will guide optimization and inform education and training of (transitional)care HCP.

5.5 - Molecular Culture for diagnosing early onset neonatal sepsis: preliminary results of the EOS-CHAMPIONS study | Jip Groen

Groen, J. (1,2,3), Prof. Benninga, M.A. (1,2,3), Dr. van der Kuip, M (4), Remijas, L. (5), Budding, D. (5), Dr. de Meij, T.G.J. (1,2,3), Dr. Niemarkt, H.J. (6)

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Rationale
The turnaround time of blood culture (BC) strongly influences the choice and duration of empiric antibiotic treatment (eAB) in suspected early onset neonatal sepsis (EOS). Many newborns receive eAB for 36-72 hours while awaiting BC results. eAB implies costly hospital admissions, promotes antimicrobial resistance and is associated with the development of various chronic conditions. Molecular Culture (MC), a broad-range PCR-based assay that detects and identifies bacterial species within 6 hours, could reduce eAB.

Methods
A diagnostic accuracy cohort study is ongoing in 8 hospitals. Infants born >32 weeks gestational age and evaluated for EOS, are eligible. An additional whole blood sample of 1mL or any smaller available volume is collected for MC analysis. Figure 1 outlines the sample collection routes. Positive BC and corresponding MC results are reported on a case by case basis. MC results were not disclosed to the clinical team in real-time.

Results
272 infants (41.5% female) have been enrolled. 13 (4.8%) infants had a positive BC, of which 5 (1.8%) were considered pathogenic and all showed clinical and biochemical signs of infection. 2 Escherichia coli and 1 Streptococcus agalactiae positive BCs were matched by MC. MC detected subthreshold Escherichia coli levels in 1 BC positive case, where only 500µl of blood was available for MC. 1 BC was positive for Streptococcus mitis/oralis, whereas MC was positive for Escherichia coli. 1 of 8 contaminant BC species was matched with MC.

Conclusion
Molecular Culture allows rapid identification of bacterial pathogens in suspected EOS, suggesting potential utility in reducing eAB.

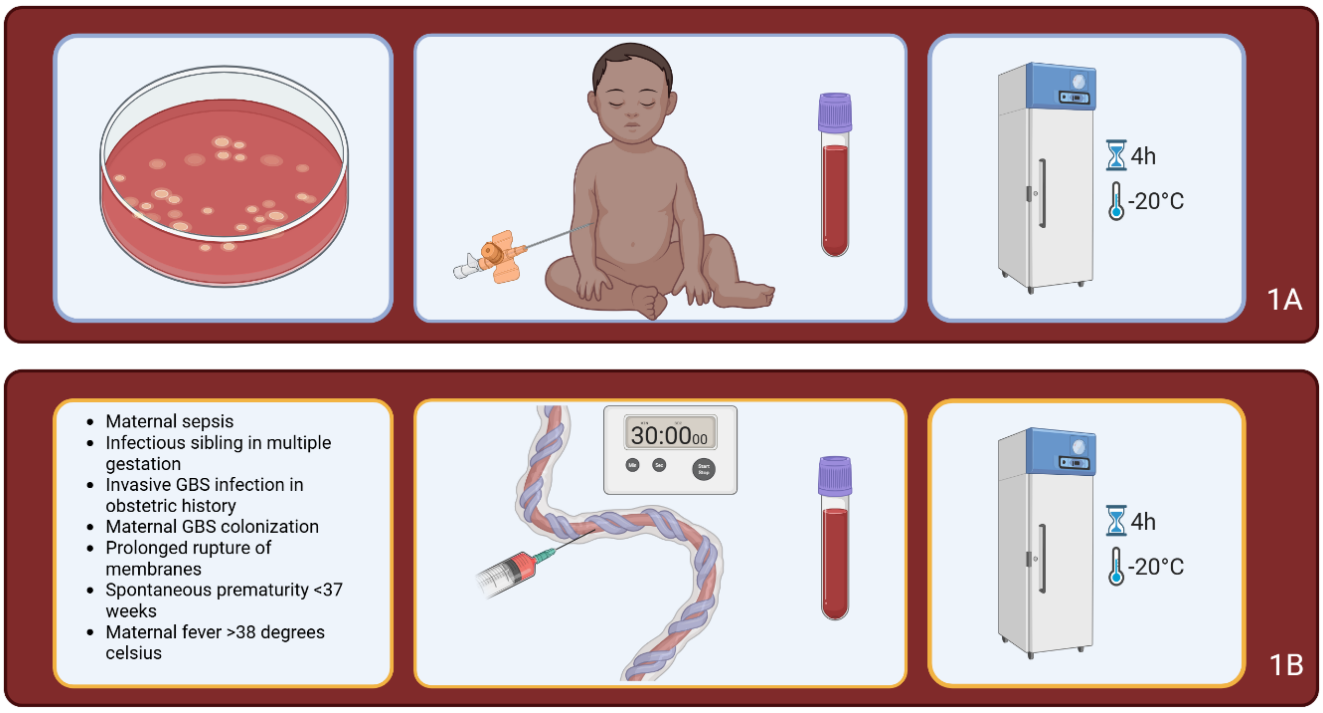

Figure 1 study sample collection routes

1A an additional blood sample is collected in infants undergoing early onset sepsis work up. The study sample is collected in the same intravenous cannulization procedure as blood culture, using the same needle. 1B in the case of positive maternal risk screening for early onset sepsis, the obstetric team collects additional umbilical cord blood within 30 minutes after birth. A time interval between study sample collection and blood culture collection exists in route 1B. Samples acquired through either route 1A or 1B are stored in the freezer within 4 hours after collection.

GBS: group B streptococcus

5.6 - Neurodevelopment at 9 years of age in moderate and late preterm infants | Lorijn de Kraker

L.C.D. de Kraker (1), A.H. Lafeber (1), C.H. Aarnoudse (2), M. Königs, J. Oosterlaan (2), J.B. van Goudoever (2,3), F. de Groof (1)

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(4) Amsterdam UMC, University of Amsterdam, Vrije Universiteit Amsterdam, Emma Children's Hospital, Clinical Neuropsychology Section, Amsterdam, The Netherlands.

Rationale
Moderate and late preterm children (MLPTI, 32 0/7 – 36 6/7 weeks) are increasingly recognized to have neurodevelopmental problems (1, 2). MLPTI lack structured follow-up programs, while follow-up programs for children born as extremely and very preterm are well established (2, 3). A recent study suggests that neurodevelopmental problems of MLPTI persist into school age, but research is limited (4).
We analyzed neurodevelopment at 9 years within MLPTI, comparing it to full-term children. In addition, we examined whether neurodevelopment at 9 years corresponds to outcomes at 2 years CA in MLPTI.

Methods
In this single-center prospective cohort study, MLPTI and full-term children were analyzed. At 9 years, children underwent neurodevelopmental assessments to determine cognitive (WISC-V-NL), motor (M-ABC-NL) and language functioning (CELF-5-NL).

Results
42 MLPTI and 26 full-term children were included. MLPTI scored lower on the standard score of the MABC-2-NL (9.2 vs 10.9, p=0.0014) and on semantic relations of the CELF-5-NL (9.6 vs 11.4, p=0.039). Also, MPLTI scored a non-significant 5 point lower on IQ of the WISC-V-NL. MP scored lower than LP on IQ (97.9 vs 108.4, p=0.007), verbal comprehension (97.1 vs 110.8, p<0.001) and fluid reasoning (97.8 vs 106.6, p=0.032). Lower cognitive scores and language scores at 2 years were associated with a lower cognitive and language score at 9 years (p=0.016; p<0.001).

Conclusion
This study showed that MLPTI have lower neurodevelopmental scores at school age, particularly those born as MP. These outcomes highlight the need for better follow-up programs and timely intervention for MLPTI, especially those born as MP.

5.7 - Effect of human milk processing in preventing CMV infection in complex human fetal intestinal mucosa organoids | Eline Freeze

Freeze, E.M.A. (1,2,3*), Johannesson, N.(1,2,3*), van den Akker, C.(2,3,4,6), van Goudoever, J.B. (1,5,6), van Elburg, R. (5), Kontopodi, E. (7), Hettinga, K. (7) , Sridhar, A. (1,2,3,8,9) & Pajkrt, D. (1,2,3,9)

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* Both authors contributed equally

Rationale
Human milk (HM) as a source of nutrition and immunity is critical for infants. Preterm neonates exhibit increased susceptibility to postnatal infections with viral, including human cytomegalovirus (CMV), and bacterial pathogens via HM. To mitigate the risk of enteric transmission, it is common practice to Holder pasteurize (HoP) HM. However, essential bioactive proteins present in HM may become denatured following HoP. Ultraviolet C irradiation (UV-C) is suggested as an alternative method to neutralize pathogens while retaining HM function.

Methods
Human fetal intestinal epithelial organoids (HIE) were cultured to form a polarized epithelial monolayer on Transwell® inserts, with intestinal fibroblasts (IF) to constitute the complex mucosal organoid model. (Un)processed HM was applied on HIE-IF model and cultured for 1h or 24h.

Results
Transcriptomic analysis revealed that UV-C treatment of HM did not significantly alter the transcriptomic profiles of the HIE-IF model, whereas HoP-processed HM induced notable changes. This effect diminishes after 24h, suggesting that the effect of HM on transcriptomics is only short term. Subsequent experiments employing shorter HM incubation times (30 minutes and 3 hours) were conducted. CMV infection was established in the HIE-IF model to further assess the effects of different HM processing methods on infected tissue. Investigations into the impact of (un)processed HM containing CMV on both the metabolomic and transcriptomic landscapes of the HIE-IF model are still ongoing.

Conclusion
UV-C processing of HM preserves the transcriptomic integrity of complex HIE-IF model, in contrast to HoP. Collectively, these findings suggest that UV-C treatment may provide superior protection against CMV intestinal infection in preterm neonates relative to Holder pasteurization.

5.8 - Oxygen saturation thresholds in children with acute respiratory distress (OxyKids): a multicentre, open, parallel-group, randomised clinical trial | Sam Louman-Slot

Sam Louman MD (1,2), Karlijn J. van Stralen PhD (1), prof Gerard H. Koppelman PhD (2,2a), Anja A. A. P. H. Vaessen-Verberne PhD (3), Jolita Bekhof PhD (4), prof Judith E. Bosmans PhD (5), Caroline L. H. Brackel PhD (6), Arvid W. A. Kamps PhD (7), Céline Mulder F. L. MD (8), Walter Balemans PhD (9), Mirjam Scheffer-Rath PhD (10), Marianne L. Brouwer PhD (11), Marije E. van den Beukel PhD (12), Marjolijn D. Akkermans PhD (3), prof Jos W.R. Twisk PhD (13, 13a), Danny Vijsma Msc (14), Esen Doganer (15), Mariëlle W. Pijnenburg PhD (16), Annemie L.M. Boehmer PhD (1,17)

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(14) Patient representative, Lung Foundation, The Netherlands
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Rationale
Oxygen saturation (SpO_2) guides oxygen therapy in children with respiratory distress. However, current thresholds lack evidence, vary widely and risk overtreatment and prolonged hospitalisations. We assessed whether an SpO_2 threshold of 88% versus 92% could safely reduce hospitalisation duration in children with acute respiratory illnesses.

Methods
In this multicentre, open-label, randomised controlled trial, children aged 6 weeks to 12 years requiring oxygen therapy for bronchiolitis, lower respiratory tract infection or acute viral-induced wheeze admitted to Dutch general paediatric wards were included. Children were assigned to an 88% or 92% SpO_2 threshold for initiating and discontinuing oxygen therapy. The primary outcome was time from admission to meeting predefined discharge criteria.

Results
Between Sept 2023 and Dec 2024, 557 children were randomised to the 88% (n=278) or 92% (n=279) group. Median time to meeting discharge criteria was 27·6h [IQR 15·1–52·7] versus 46·6h [24·2–85·1] (adjusted difference 16·8h; 95%CI 12·1–20·8; p<0·0001), in the 88% and 92% group respectively. Median hospital stay was 39·8h [22·0–67·2] versus 60·8h [38·5–95·8] (adjusted difference 17·6h; 95%CI 12·5–22·6; p<0·0001). Oxygen therapy was started less often and if started, duration was significantly shorter in the 88% group. Serious adverse events, post-discharge health care visits, time to disease recovery, and parental anxiety did not statistically differ between groups.

Conclusion
Adoption of an 88% SpO2 threshold in hospitalised children 6 weeks to 12 years old with acute respiratory illness in routine general paediatric care, safely shortens hospitalisation time and reduces treatment burden across a broad range of respiratory diagnoses.

5.9 - Efficacy and Safety of Non-Pharmacological Treatments for Paediatric Functional Constipation: A systematic review and meta-analysis | Anna de Geus

Arruda Navarro Albuquerque, D. (1)*, de Geus, A. (2,3,4)*, Gordon M. (1), Sinopoulou, V. (1), Khan, M. (1), Ajiboye, A. (1), Liu, S. (1), Benninga, M.A. (2), Tabbers M.M. (2)

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(2) Emma Children's Hospital, Amsterdam University Medical Centers (AUMC), University of Amsterdam, Paediatric Gastroenterology, Amsterdam, The Netherlands
(3) University of Amsterdam, Amsterdam UMC, Amsterdam Gastroenterology Endocrinology Metabolism, The Netherlands
(4) University of Amsterdam, Amsterdam UMC, Amsterdam Reproduction and Development research institute Amsterdam, The Netherlands

Rationale
To systematically review the efficacy and safety of non-pharmacological therapies for functional constipation in children.

Methods
PubMed, MEDLINE, Embase, PsycINFO were searched to March 2025. Randomized controlled trials (RCTs) including children (0–18 years) with FC treated with non-pharmacological interventions compared to placebo, no treatment, or other interventions were included. Primary outcomes were treatment success, defecation frequency, and withdrawals due to adverse events. Dual data extraction and appraisal was conducted. Certainty was assessed using GRADE.

Results
Ninety-three RCTs comprising 7,787 children (50.4% female) were included investigating dietary, psycho-educational, physiotherapeutic interventions, various complementary and alternative medicine interventions, and electrical stimulation. A substantial part of the therapies provided evidence that was of very low certainty, meaning no conclusions could be drawn. Abdominal transcutaneous electrical stimulation (ATES) plus pelvic floor muscle exercises (PFME) may improve treatment success and defecation frequency compared to PFME alone (RR:1.75 [95%CI 1.25–2.44], and MD:1.85 [95%CI 1.28–2.43], moderate certainty). Percutaneous tibial nerve stimulation (PTNS) plus PFME leads to more treatment success (RR:1.73 [95%CI 1.08–2.77], low certainty) and greater defecation frequency (MD:1.82 [95%CI 0.82–2.82], moderate certainty). Behavioural therapy plus PEG may have no treatment success (RR:0.83 [95%CI 0.62–1.12], low certainty) and probably reduces defecation frequency (MD:-1.80 [95%CI -2.88 – -0.72], moderate certainty).

Conclusion
Imprecise data, poor reporting, and substantial heterogeneity led to downgrading in GRADE assessments. Some non-pharmacological treatment options for children with FC show beneficial effects and these may be considered in the management of children. Future trials should aim to improve methodological rigor.

6. Café DeLaMar

14:00 - 15:20

	Abstract titel	Auteur
6.1	A GWAS meta-analysis to uncover the molecular etiology of posterior urethral valves.	*Lisanne Vendrig*
6.2	Prediction and implementation of a machine learning model for bronchopulmonary dysplasia using vital sign data from the first seven days after birth.	*Frank Bennis*
6.3	An advanced human intestinal model for studying host-pathogen interactions, antiviral therapies, and multiorgan dynamics	*Joep Korsten*
6.4	Effective communication in pediatric palliative care from the perspectives of parents and children: A systematic review	*Leonie la Rondelle*
6.5	RHINE: A Comparison of Age at Diagnosis and Clinical Outcomes in Rare Kidney Stone Forming Diseases (ERKNET x OxalEurope)	*Laila Oubram*
6.6	External Validation of a Machine Learning Prediction Model for Late-Onset Neonatal Sepsis	*Hugo Koppens*
6.7	Insights in structure and communication within pediatric palliative care networks: a social network analysis	*Sophie Tooten*
6.8	Probiotic supplementation modulates fecal metabolites in extremely preterm infants, revealing potential mechanisms of action against necrotizing enterocolitis	*Aranka van Wesemael*
6.9	Blended Tube Feeding in Children: Parental Perspectives and Experiences	*Renee Boereboom*

6.1 - A GWAS meta-analysis to uncover the molecular etiology of posterior urethral valves | Lisanne Vendrig

Vendrig, L.M. (1), Lim, T.Y. (2), Tanck, M.W.T. (3), Maj, C. (4), Groothoff, J.W. (1), Levtchenko, E.N. (1), Van der Zanden, L.F.M. (5), Sanna-Cherchi, S. (2), Chan, M.M.Y. (6), Hilger, A.C. (7,8), Westland, R. (1).

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(5) IQ Health Science Department, Radboud university medical center, Nijmegen, The Netherlands.
(6) Medical Research Council Laboratory of Medical Sciences, Imperial College London, London, United Kingdom.
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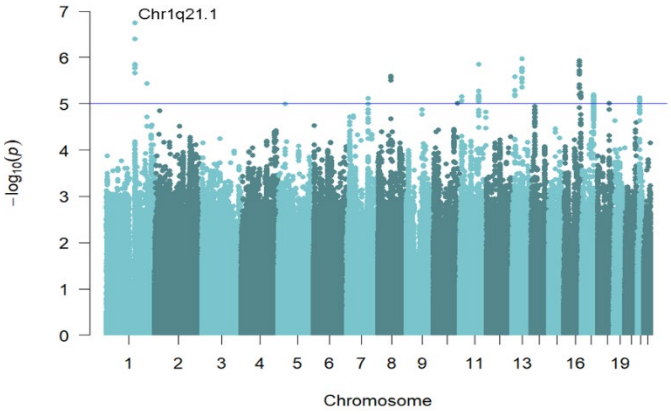
(8) Research Center on Rare Kidney Diseases (RECORD), University Hospital Erlangen, Erlangen, Germany.

Rationale
Posterior urethral valves (PUV) are the commonest cause of kidney failure in boys. Although a genetic origin is suspected for PUV, its molecular etiology remains largely unknown. Hence, we performed a genome-wide association study (GWAS) meta-analysis of three study cohorts to better characterize the role of common variants in PUV.

Methods
Summary statistics from two previously published GWAS (Van der Zanden, 2022; Chan, 2022) were combined with an additional unpublished cohort. In total, 1,037 PUV cases and 17,170 matched controls were included. All cases and controls were male and of European ancestry. Variants were called using DNA microarray genotyping (948 cases, 8,823 controls) or whole-genome sequencing (89 cases, 8,347 controls). Quality control included standard measures. Genome-wide logistic regression analysis was performed with principal components as covariates. 4,694,037 autosomal variants were analyzed using the inverse-variance approach in METAL.

Results
14 loci showed suggestive association ($P < 10\text{-}5$) with PUV. The variant with the strongest association (OR 0.70, 95% CI 0.61-0.80, $P = 1.81 \times 10\text{-}7$) was located at the Chr1q21.1 region that is associated with known genomic disorders (OMIM #612474/612475). Large and rare duplications at this locus have previously been implicated in PUV. Further post-GWAS analyses are pending.

Conclusion
In this large-scale European GWAS meta-analysis in PUV, suggestive association was seen at 14 loci. The strongest association was found within a genomic disorder locus for PUV, potentially influencing gene dosage. Additional analyses will be performed and presented.


Chr1q21.1
7
6
5
4
3
2
1
0
$-\log_{10}(p)$
1
2
3
4
5
6
7
8
9
11
13
16
19
Chromosome

6.2 - Prediction and implementation of a machine learning model for bronchopulmonary dysplasia using vital sign data from the first seven days after birth. | Frank Bennis

Frank C Bennis (1,2,3), Wes Onland (2,4), Joris P van der Vorst (1), Mark Hoogendoorn (5), Gerard J. Hutten (2,4), Anton H. van Kaam (2,4), Jaap Oosterlaan (1,2), Marsh Königs (1,2)

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(4) Amsterdam University Medical Centers, Emma Children's Hospital, Department of Neonatology, Amsterdam, The Netherlands
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Rationale
Bronchopulmonary dysplasia (BPD) is a serious complication of preterm birth. Systemic corticosteroids can reduce BPD risk but carry significant adverse side-effects, necessitating targeted treatment for high-risk infants. In current practice, only 25% of affected patients receive corticosteroids. This study aims to implement a machine learning (ML) model using vital sign timeseries to predict BPD within the first week after birth, guiding targeted treatment.

Methods
Retrospective data from a neonatal intensive care cohort (2009-2015) were analyzed, including infants with gestational age <30 weeks who survived to 36 weeks postmenstrual age. Clinical and vital sign timeseries data (respiratory support mode, FiO2, SpO2) were collected. Vital sign features were compressed with an autoencoder and combined with clinical data using a long short-term memory neural network. Implementation included automatic clinical data extraction, processing, prediction, feedback to EPIC and continuous dashboard monitoring. The Youden index determined the optimal sensitivity and specificity threshold using 2023-2024 data. Model performance was compared to prescriptions in current practice (Jan-Aug 2025).

Results
Of 513 patients, 102 (19.8%) developed BPD. The model achieved an AUC of 0.83 (95%CI 0.81-0.84) and 51% specificity at 90% sensitivity, replicated in 2023-2024 data. Prospectively, the model predicted BPD in 9 (8 severe, 1 mild), of which 2 received corticosteroids, matching the 25% treatment rate. No false positives occurred.

Conclusion
The ML model offers clinically valuable, validated BPD predictions and is feasible to implement in clinical care. Prospective use may double early preventative treatment rates in high-risk infants compared to current practice.

6.3 - An advanced human intestinal model for studying host-pathogen interactions, antiviral therapies, and multiorgan dynamics | Joep Korsten

Joep Korsten (1,2), Alessandro Dei (3), Carlemi Calitz (1,2), Nina Johanneson (1,2), Eline Freeze (1,2) , Eloi Mercier (4), Allen Eaves (3,4,5), Sharon Louis (4), Ryan Conder (4), Wing Chang (4), Dasja Pajkrt (1,2,6), Katja C. Wolthers (1,2), Salvatore Simmini (3), Adithya Sridhar (1,2,6)

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(6) Emma Center for Personalized Medicine, Amsterdam UMC, Amsterdam, The Netherlands

Rationale
The absence of a physiologically relevant intestinal infection model for various viruses limits the ability to dissect viral infection dynamics and host-pathogen interactions within the human adult/foetal/paediatric intestinal mucosa. This mucosal barrier plays a central role in pathogen defence while also regulating nutrient absorption and drug metabolism. Advances in single-cell analysis tools have highlighted the diverse contributions of key mucosal cell populations to immune surveillance and homeostasis. However, recapitulating this cellular complexity in vitro remains a major challenge.

Methods
To address this gap, we developed a human intestinal model in which intestinal epithelial cells, fibroblasts, and antigen-presenting cells (APCs), such as dendritic cells (DCs), are integrated. This co-culture system enables the study of barrier function, inflammatory responses, viral infections, and antiviral interventions in vitro.

Results
Our model successfully recapitulates key physiological features of the human gut mucosa, including extracellular matrix deposition, Paneth cell differentiation, and immune interactions. These features enhance its relevance for investigating pathogenesis and host immune responses. As proof of principle, we demonstrate that the model improves the efficiency of Enterovirus A71 (EV-A71) replication and showcases its potential for antiviral screening.

Conclusion
The advanced co-culture model enables the exploration of epithelial-mesenchymal-immune crosstalk and its role in intestinal health and disease. Furthermore, we are working on combining this model with the blood-brain barrier (BBB)-brain model to create a multi-organ culture and infection system. This innovative approach opens new avenues for studying systemic interactions in multi-organ systems, paving the way for transformative research in infection dynamics and therapeutic discovery.

6.4 - Effective communication in pediatric palliative care from the perspectives of parents and children: A systematic review | Leonie la Rondelle

La Rondelle, L. (1), Engel, M. (1), Brunetta, J. (1), Teunissen, S.C.C.M. (1), Aris-Meijer, J.L. (2), Ahout, I.M.L. (3), Fahner, J.C. (4) & Kars, M.C.(1)

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(2) University Medical Center Groningen, Beatrix Children's Hospital
(3) Radboud university medical center, department of pediatrics, Amalia Children's Hospital
(4) University Medical Center Utrecht, Wilhelmina Children's Hospital

Rationale
In pediatric palliative care (PPC), effective communication is essential for providing appropriate care. A safe and inviting interaction with healthcare providers (HCPs) enables children and parents to share their needs and preferences for treatment and care. However, children and parents often experience a lack of appropriate communication. This literature review aims to identify the perspectives of children with an advanced life-limiting illness and their parents on how HCPs can communicate effectively.

Methods
A systematic review was conducted in the databases PubMed, Embase and CINAHL. Empirical studies (2016-2024) on experiences with verbal and non-verbal communication, including descriptions of attitudes, behaviors, and communication interventions, were searched. Data were analyzed thematically.

Results
A total of 52 publications was included, describing experiences with PPC communication in general or specifically related to diagnosis, prognosis, advance care planning, or end-of-life discussions. Key elements of effective communication for children and parents include: feeling informed and empowered by the HCP, experiencing that the HCP conveys hope and optimism, is empathetic and caring, fosters and maintains the care relationship, demonstrates professionalism and expertise, and ensures adequate communication among collaborating HCPs. Attention to and respect for the environment and resilience of the child and parents enhance trust, strengthen the bond, create space for hope, and provide control and support.

Conclusion
Regardless of the stage of illness, children and parents emphasize the importance of person-centered communication. Implementing interventions that support HCPs in communicating more effectively with children and parents throughout the entire disease trajectory warrants further research to improve the quality of PPC.

6.5 - RHINE: A Comparison of Age at Diagnosis and Clinical Outcomes in Rare Kidney Stone Forming Diseases (ERKNET x OxalEurope) | Laila Oubram

Laila Oubram (1), Franz Schaefer (2), Stefanie Häberle (2), Aude Servais (3), Shabbir S. Moochhala (4), Jaap W. Groothoff (1), on behalf of the OxalEurope Consortium

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(4) UCL Department of Renal Medicine, Royal Free Hospital, London, UK

Rationale
Primary hyperoxaluria type 1 (PH1), Dent disease, and cystinuria are rare inherited kidney stone disorders that often lead to chronic kidney disease (CKD) and renal failure. Delayed diagnosis may critically impact disease progression and renal outcomes. The RHINE project aimed to quantify diagnostic delays across Europe, assess their association with renal outcomes, and compare these findings among three rare stone-forming disorders.

Methods
Data were combined from the OxalEurope registry and ERKReg, comprising 1077 patients with PH1, 657 with cystinuria, and 140 with Dent disease. Variables analyzed included age at first symptoms, age at confirmed diagnosis, diagnostic delay, kidney function (eGFR, CKD stage), kidney stone events, renal replacement therapy (RRT) requirement, and therapeutic interventions. Geographic variation in diagnostic delay across European countries was also evaluated.

Results
The median age at diagnosis was 7.2 years for PH1, 8.2 years for Dent disease, and 12.8 years for cystinuria. The median diagnostic delay was 1.2, 1.5, and 0.5 years, respectively. Considerable inter-country variability was observed, with longer delays in some regions. Early diagnosis correlated with better preservation of renal function.

Conclusion
Diagnostic delay remains a significant issue in rare stone diseases and varies considerably across European countries, particularly in PH1. The availability of novel therapies such as RNA interference (iRNA) for PH1 underscores the urgency of timely diagnosis. Harmonized diagnostic pathways are essential to improve outcomes and ensure equitable access to emerging treatments across Europe.

6.6 - External Validation of a Machine Learning Prediction Model for Late-Onset Neonatal Sepsis | Hugo Koppens

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Rationale
Late-onset sepsis (LOS) and necrotizing enterocolitis (NEC) are major causes of morbidity and mortality in very preterm infants, yet early recognition remains difficult due to nonspecific symptoms. Machine learning (ML) may support earlier detection. This study externally validated a previously developed ML model for early prediction of LOS and NEC.

Methods
In this retrospective cohort study following TRIPOD+AI guidelines, 1,168 infants born before 32 weeks' gestation admitted to two Dutch NICUs (Amsterdam UMC and Erasmus MC) were analyzed. Continuous vital-sign monitoring and clinical data generated ML-based probability scores for LOS and NEC every 15 minutes. Outcomes were recall (sensitivity), precision (positive predictive value), and time gain before diagnosis. Secondary analyses assessed performance by gestational age, postnatal age, and sepsis category (proven vs clinical), as well as detection of severe episodes (nSOFA ≥ 4).

Results
The model analyzed 2.75 million probability scores across 29,508 admission days. Among 1,168 infants, 330 (27%) experienced at least one LOS or NEC episode. At a low threshold (0.15), recall was 58%, precision 10%, and median time gain 11.6 hours before diagnosis. Higher thresholds increased precision (up to 21%) but reduced recall (to 22%). Compared with internal validation, recall was lower (69% vs 58%), while precision (5% vs 10%) and time gain (10.0 vs 11.6 hours) improved.

Conclusion
External validation confirmed consistent model performance across centers. Although results suggest clinical promise, limited precision raises concern for alarm fatigue and underscores the need for integration with clinical assessment. Prospective evaluation should confirm predictive value, generalizability, and clinical impact before implementation.

Table – Model performance

Threshold	True positives	Recall	Precision	Time gain (hours) median [IQR]
0.15	287	58%	10%	11.6 [4.0 - 21.6]
0.25	248	51%	12%	9.9 [3.7 - 21.1]
0.50	171	35%	17%	7.2 [2.5 - 18.4]
0.75	108	22%	21%	5.2 [1.9 - 13.4]

6.7 - Insights in structure and communication within pediatric palliative care networks: a social network analysis | Sophie Tooten

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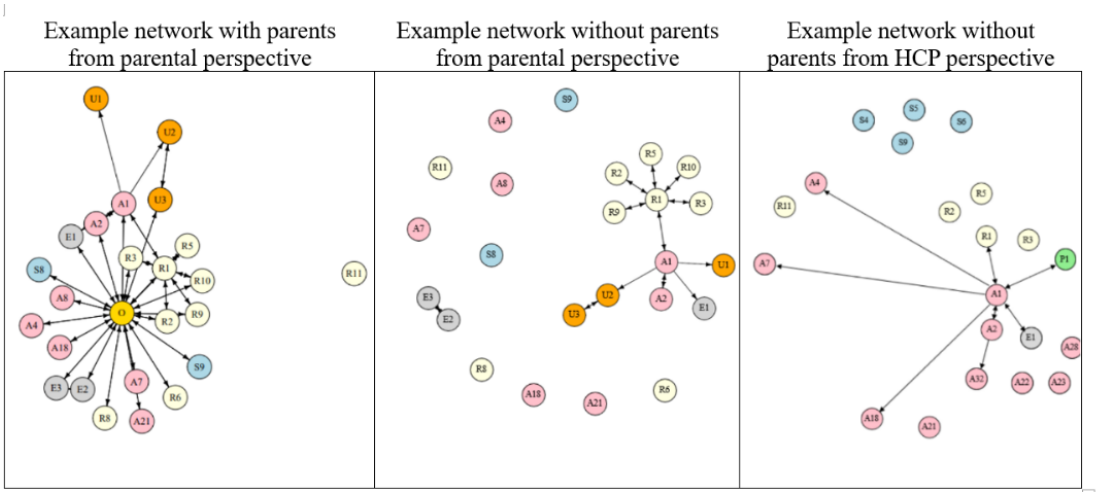
Rationale
Pediatric palliative care is delivered by multiple healthcare providers (HCPs) across various organizations and care levels. Due to the rarity and complexity of this care, unique collaborations among a large number of HCPs are essential. This study explores the structure and communication within these networks to inform strategies for improving multidisciplinary collaboration in pediatric palliative care.

Methods
A case study among parents and HCPs of children receiving palliative care at the Amalia Children's Hospital was conducted using social network analysis. Structured interviews were used to map care networks and communication patterns within these networks, based on parents' perspective. Involved HCPs completed a questionnaire capturing their perspectives on the care network. The primary treating physician's network was visually represented. Differences between the mapped networks in network size, number and type of HCPs and communication patterns were analyzed descriptively.

Results
Nine children were included, with 15 parents interviewed and 69 of 182 HCPs completing the questionnaire. Network analysis revealed that parents play a central role in communication between HCP's; without them significant communication gaps would occur. Parent-reported networks included more HCPs (median: 22 vs. 11), with limited overlap in the providers identified by both parents and HCPs (median Jaccard index 45). Communication between healthcare organizations often relied on a single HCP as a liaison.

Conclusion
Pediatric palliative care networks are large and complex. Parents are essential for the transfer of information within these networks. A lack of shared overview on the HCPs involved may hinder effective collaboration between and with HCPs.



6.8 - Probiotic supplementation modulates fecal metabolites in extremely preterm infants, revealing potential mechanisms of action against necrotizing enterocolitis | Aranka van Wesemael

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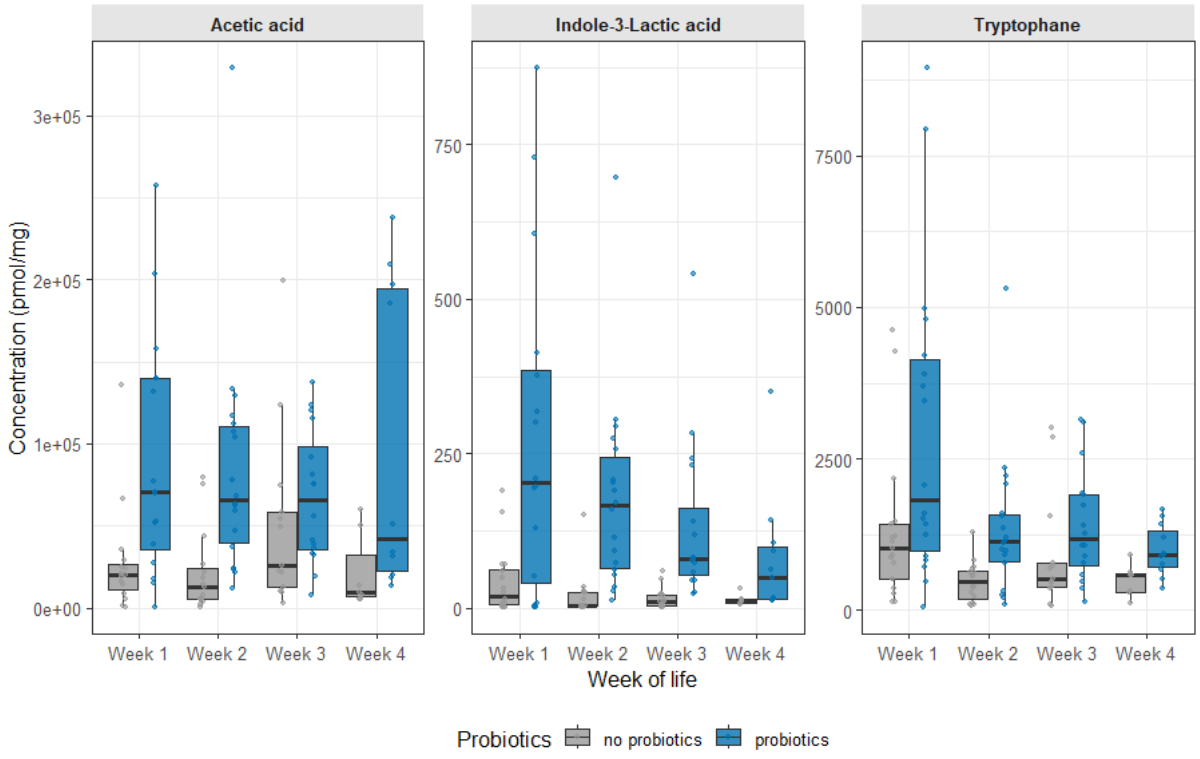
Rationale
The recent implementation of routine use of a multistrain probiotic (ProPrems®) in very preterm infants in the Netherlands is associated with a 50% reduction in necrotizing enterocolitis (NEC). Emerging evidence suggests that metabolic activity of the microbiota may play a role in explaining the benefits beyond influencing microbiota composition. This study aims to examine short-chain fatty acid (SCFA) and tryptophan (Trp) metabolism alterations related to ProPrems® supplementation.

Methods
Extremely preterm infants, with and without probiotics, were included in two Dutch NICUs (2021-2024). Fecal samples collected from week 1 through 4, were analyzed through liquid-chromatography-tandem-mass spectrometry to quantify SCFAs and Trp metabolites. Log_2-transformed concentrations were compared using mixed-effects linear models with covariate adjustment (week of life, patient identification, birthweight, feeding status and antibiotic exposure) and false-discovery rate correction.

Results
Thirty-five infants (18 probiotics, 17 non-exposed controls; median gestational age 26+5; 116 fecal samples) were included. In the probiotic exposed infants, total SCFA levels were higher, mainly due to increased acetate concentrations (adjusted fold change (aFC) 3.5, adj.p < 0.001). Additionally, Trp and Indole-3-Lactic acid concentrations were significantly increased (aFC 2.1, adj.p < 0.05; aFC 6.2, adj.p < 0.001; Figure 1).

Conclusion
Supplementation with ProPrems® significantly impacts the fecal metabolic profiles, with increased acetate, Trp and indole-3-lactic acid concentrations in exposed infants. These metabolites have been linked to improved gut barrier function, which may explain the established protective effects. Future studies should assess whether these metabolic changes differ in infants who develop NEC, to clarify probiotic mechanisms, and inform future pro- and postbiotic strategies.

Figure 1. Fecal concentrations of three metabolites significantly differing between probiotic-exposed and unexposed groups across weeks of life. Boxplots display concentrations (pmol/mg dry matter) per group and sampling week, illustrating temporal trends and probiotic-associated increases.



6.9 - Blended Tube Feeding in Children: Parental Perspectives and Experiences | Renee Boereboom

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Rationale
Blended tube feeding (BTF), enteral nutrition based on whole-foods, is increasingly adopted by parents of children requiring long-term tube feeding (TF), driven by perceived benefits in feeding tolerance, family inclusion, and quality of life. However, systematic data on parental experiences in Europe are lacking. This study explored parental perceptions and experiences with BTF in the Netherlands.

Methods
A nationwide cross-sectional online open-link survey was conducted between March and July 2025 among parents/caregivers of tube-fed children. This 35-item questionnaire addressed TF history, BTF familiarity and practice, and informational needs. Data were analyzed descriptively.

Results
In total, 205 surveys were completed by parents or caregivers. Median child age was 5 years and genetic/congenital disorders predominated as underlying disease. Familiarity with BTF was high (67.3%), and 48.8% used it, mainly as home-prepared blends from family-meals. Improved TF tolerance was the main reason for initiation, while lack of knowledge of BTF was the main barrier. Reported benefits included better TF tolerance (76.0%), reduced reflux/vomiting (54.0%), and improved stool patterns (47.0%); negative experiences primarily concerned caregiver burden (44.0%). Most parents reported positive experiences and willingness to recommend BTF (86.0% and 92.0%, respectively). Only one-third had received formal information, while many relied on social media, and 58.7% rated provider knowledge as insufficient.

Conclusion
This nationwide survey demonstrates high parental familiarity and satisfaction with BTF but highlights unmet needs for professional guidance and reliable information. Together with the companion professional survey, these findings underscore the need for coordinated, evidence-based, and family-centered BTF support in pediatric care.