



Nordisk forening for Funksjonshemming og oral Helse (NFH)

Bulletin

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Ordföranden har ordet

NFH Bulletinen ser litt annerledes ut denne gang. Det beror på at vår redaktør under 14 år, Lena Romeling, gikk i pensjon i sommer og styret i NFH Norden søker etter en ny redaktør. Vi har ennå ikke landet og utpekt en ny redaktør, men håper å ha vedkommende på plass til neste nummer av Bulletinen våren 2023. Da håper vi at Bulletinen er tilbake til sin velkjente design.

Et stort takk for all innsats med Bulletinen under alle år retter vi til **Lena Romeling** og ønsker henne en skjønn pensjonist-tilværelse.

Hele denne utgave av Bulletinen er viet referat og rapporter fra iADH konferansen i Paris i august 2022. Dersom man ønsker å lese abstrakts av alle presentasjoner og postere som ble presentert under konferansen er disse publisert som en pdf-fil på iADHs hjemmeside www.iadh.org/wp-content/uploads/2022/09/iADH-2022-Conference-France.pdf.

Hovedredaktør for dette arbeidet har vært Dr. Sharat Chandra Pani from London Ontario, Canada.

Bulletinen er et viktig instrument for å spre informasjon om kronisk sykdom, funksjonsnedsettelse og oral helse. Det er viktig at vi får inn bidrag til kommende nummer av Bulletinen fra alle medlemsland i Norden. Redaksjonen ønsker seg for eksempel referat eller rapporter fra kurs eller symposier, forskningsrapporter, anmeldelser av viktige nye fagbøker, eller autoreferat av mastergrads- eller doktorgradsavhandlinger. Husk at fotografier av forfatteren, foredragsholderne, fotografier fra kurset/kongressen, eller av ting som er omtalt i artikkelen er varmt velkomment.

Legg gjerne en utskrift av dette nummer av Bulletinen på lunsjrommet og la dine medarbeidere på arbeidsplassen også få ta del av innholdet. Prøv også å engasjere flere av dine medarbeidere til å bli medlemmer i NFH slik at vi derved kan øke kunnskapen og forståelsen for oral helse hos personer med funksjonshemminger og sammensatte behov.

Ta god vare på hverandre i denne vanskelige tid i Europa og Ukraina for oss som medmennesker og tannhelsepersonell. Fra hele styret i NFH Norden ønsker vi dere en riktig god jul og et godt nytt år.

Stefan Axelsson, Formann

XXV Nordisk Møte i NFH med Generalforsamling 2023

(August 30th to September 1st, 2023)

Vi har nå åpnet opp for tidlig påmelding ("early bird") til kongressen – se www.nfh-nordic2023.com.

Vi gleder oss til å få se alle i Oslo etter sommeren 2023!



Neste iADH Conference 2024 blir i Seoul, Sør-Korea

Since 1970, iADH has hosted a biennial congress that provides members from all over the world with an opportunity to assemble in one place, and share their scientific knowledge and collective experience to improve desired oral health outcomes for people with disabilities. During International conference, eminent speakers from around the world cover hot issues in Special Care Dentistry, bringing both state of the art knowledge and practical advice along with a fun and friendly social programme. Our 24th IADH Congress will be Seoul, Korea in 2024 26th-29th September. The theme is Bridging the Gap in Dental Care for Persons with Disabilities - Now and Beyond.



Find out more: www.iadh.org/event/iadh-conference-seoul-2024



iADH 2022
PARIS FRANCE

26th 23/26 August
International Association
For Disability & Oral Health

De følgende sidene kan du lee referat fra noen av de parallelle sesjonene under kongressen fordelt på de 3 dager kongressen varte. Referatene er skrevne av kollegaer fra de ulike nordiske land og vær referent står ansvarlig for referatets innhold.

Du kan se mer stoff i form av nyheter, keynote presentations, og fotografier og videos fra kongressen og fra ulike sosiale aktiviteter på iADHs hjemmeside under arkfanen NEWS.

Som en innledning til de nordiske referatene legger vi med innledningsordene fra president for iADH Dr. Alison Dougall:



Editorial from President of iADH 2020 - 2022

It is my great pleasure as President of iADH to present the proceedings and abstracts for the 26th IADH Congress to be held in Paris, France under the auspices of Santé Orale et Soins Spécifiques (SOSS). The meeting is entitled 'Quality Matters' Quality of healthcare is a key component of the route to equity and dignity for people with disabilities and disadvantages yet people with disabilities remain largely absent from mainstream health research, through poorly justified exclusion criteria and inaccessible study design. Thankfully, the necessity for inclusion of traditionally under-represented groups in research is receiving increasing attention with growing concern over the appropriateness of translating research conducted with narrow groups of participants that do not represent the demographics of society in which we live. Taking the road less travelled, the iADH is a global organisation with over 8000 members from all sectors of health and social care specifically interested in disability and oral health. Since 1970, iADH has hosted a biennial congress that provides members from all over the world with an opportunity to assemble in one place, and share their scientific knowledge and collective experience to improve desired oral health outcomes for people with disabilities. iADH recognise that Quality oral care has to be based on scientific knowledge and this abstracts book highlights contributions from world-class keynote speakers and showcases of the best available research in Special Care Dentistry.

www.iadh.org/wp-content/uploads/2022/09/iADH-2022-Conference-France.pdf

Onsdag 24. august 2022

OPENING CEREMONY

First Key Note Speaker var Philippe Aubert **“Quality matters: Defining quality of care.”**

Philippe er født med CP og lever med bevægelses indskrænkninger samt spasticitet, og han har ingen talefunktion men kommunikerer via voice speak på sin computer.

PA har fået foretaget store tandbehandlinger – i starten oplevede han det som overgreb, men gradvist har nogle behandlinger kunnet lade sig gøre med god kontakt og information.

Vigtigt er relation mellem patient og behandler, at lytte til pt kræver god relation, tid og gerne hjælp af en bisidder eller familie.

Det er vigtigt, at pt selv har så meget som mulig medbestemmelse vedrørende tandbehandlingen.

Tænderne har meget stor indflydelse på udtrykket i ansigtet – det er mere end tænder, til at spise med - ansigtets fremtoning giver også ære og værdighed samt har stor værdi for socialisering.

Der skal være respekt frem for distance i behandlersystemet og det er essentielt med en ”caring attitude”:

Dental care frem for Dental management.

Disability er ofte en byrde, men AP vil gerne føle sig velkommen og lyttet til og han omtaler forholdet mellem individets sårbarhed, autonomi og inklusion, – ord er ikke uskyldige.



Internationalt har handikappede uensartede muligheder for tandbehandlinger og økonomi hertil afhængig af forholdene i de enkelte lande.

Philippe Aubert mener at der via United Nations bør arbejdes internationalt for at opsætte forskningsprotokoller

24.08.2022 SEMINAR - Communication in SCD

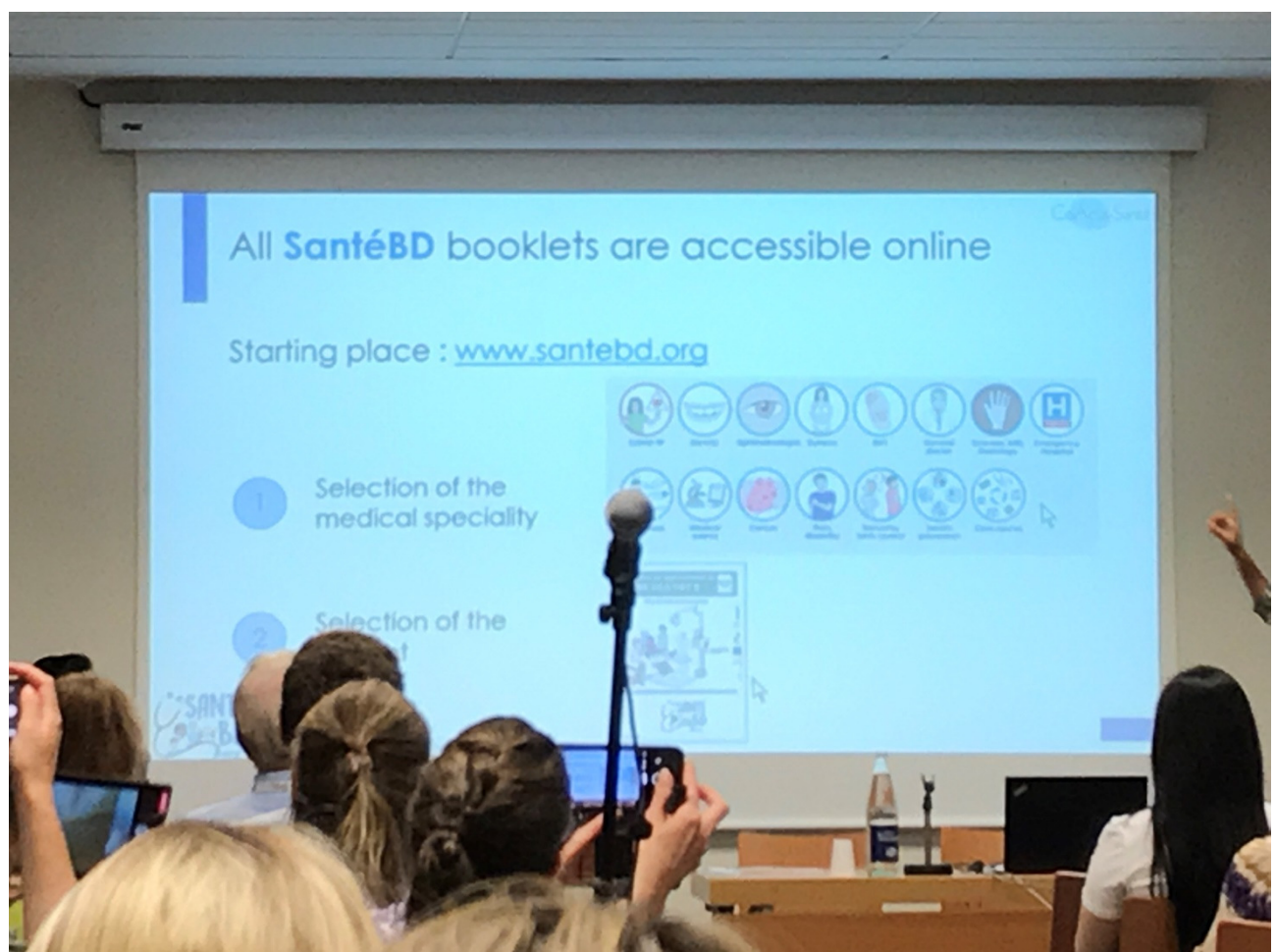
People are different and so are people with needs of special care. In this session, 3 different situations were addressed.

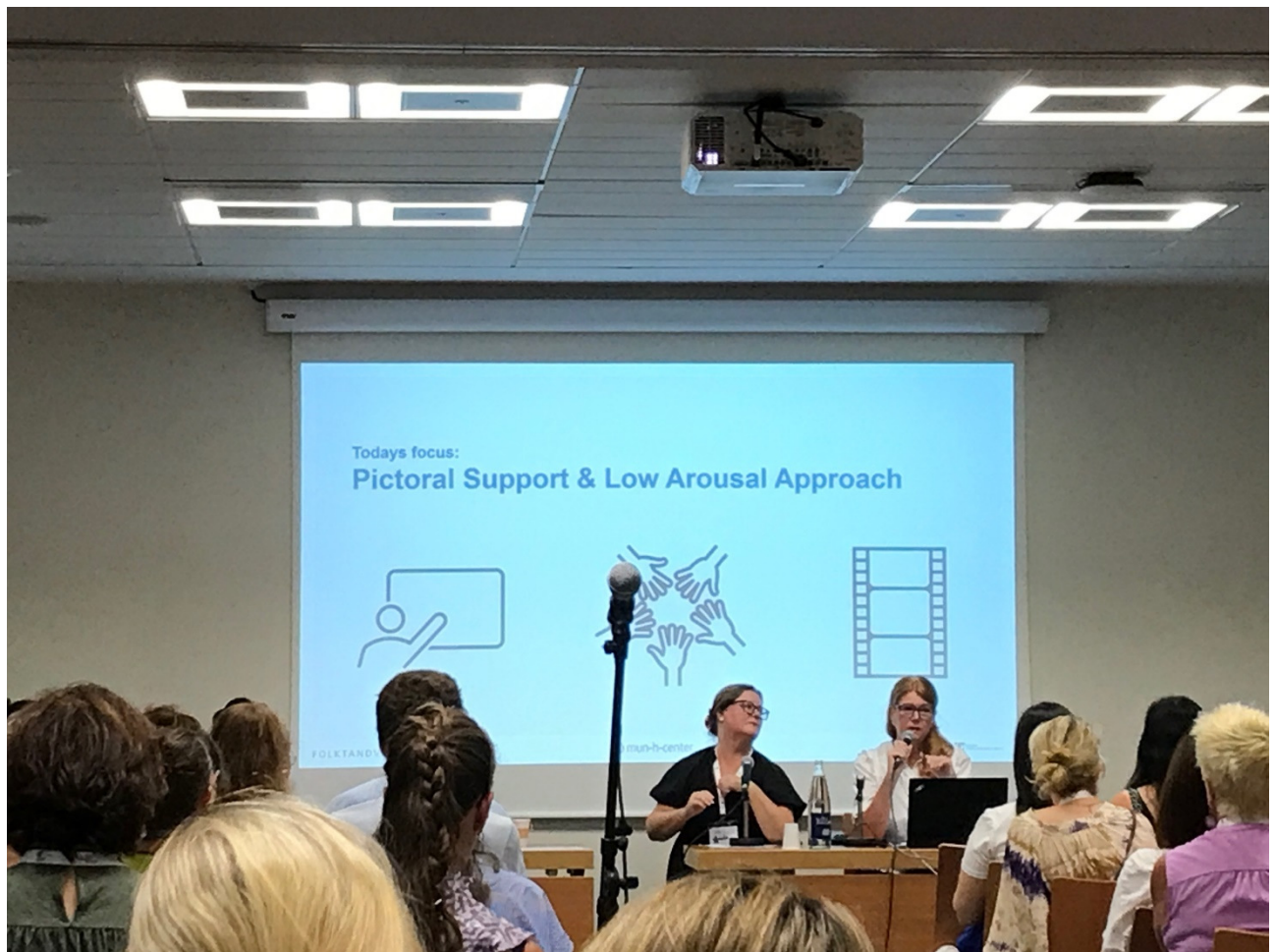
The first issue was how to communicate with people with little or low hearing ability. There were short and ready to use advice on how to improve communication. Ex. God light, no music, talk with normal rhythm and use normal patterns of speech. Do not put fingers near your face, don't use gum and don't yell. In addition, do not be afraid to ask how the person in front of you prefer to communicate and be sure that the person can understand.



Next speaker talked about tools to provide a better communication for people with different kind of disabilities in general. Studies have shown that many do not come to their dental appointment because of fear and anxiety because they do not understand what is going to happen.

The French organization CoActis Santé had developed a booklet of pictograms and images free to download to improve understanding and prepare a person on of what will happen. There are 14 different booklets to cover dental treatments and more to come. It is now translated to 6 languages.





The third speaker talked about a low arousal approach creating a safe and comforting dental appointment by using three principles

1. Take responsibility, cooperate instead of dominance
2. Take control. The patient has to feel that they have a saying, and can be understood
3. Emotions reflects. Good energy effects the people around

Sometimes it can take a long time and many appointments to get to a state of trust, and it requires a lot of cooperation with parents and health caretakers but it is a good investment in the future, and the price will be paid off in the long turn.

24.08.2022 SEMINAR -The significance of oral health in older age

Colman Mcgrath, faculty of Dentistry, the University of Hong Kong: Succesful ageing and oral health

Der bliver flere ældre generelt i verden og snart er der flere mennesker over 60 år end under 6 år. FN har gjort ti-året 2021-2030 til "Decade of healthy ageing" med 4 fokuspunkter: a. Ældrevenlige miljø b. Bekæmpe aldersdiskrimination c. Integreret omsorg og d. Langtidsomsorg. Under punkt c er der specifikt nævnt tandpleje og vigtigheden af nem adgang uden ekstra økonomisk udgift til profylakse, behandling og palliativ behandling. Der er ikke meget forskning på området med aldring og oral sundhed, og den der er, henviser til at jo færre mistede tænder jo længere er overlevelsestiden og samtidig har borgere med tanderstatning længere overlevelse end tandløse uden erstatning. I forhold til ernæring viser forskning at jo færre tænder jo større fejlnæring.

Gerry McKenna, Queens University Belfast: The role of oral health in maintaining nutritional intake for older adults

Ved tandtab sker nedsat oral funktion, reduceret tyggefunktion, reduceret bidkraft og påvirkning af fødevarevalg. Tanderstatninger i sig selv ændrer ikke på ernæringen, det er vigtigt med samtidig vejledning i ernæring og vaneændring.

Frauke Müller, University of Geneva, Schweiz: Periodontitis and peri-implantitis in older dependent people

Periodontitis og periimplantitis findes oftere hos ældre end hos yngre mennesker og de 71-80 årige har den største stigning i implantatbehandling. Infektioner som periodontitis kan fremme udviklingen af kroniske systemiske sygdomme og det er vist at behandlingen af periodontitis kan bedre den generelle sundhed end ved diabetes. Det er også velkendt at en mulig konsekvens ved nedsat oral sundhed er lungebetændelse pga aspiration af mundhulebakterier. Den funktionelle nedsættelse hos mange ældre at plak ikke mærkes eller lugtes og den nedsatte motoriske funktion gør at renhold af munden bliver vanskeligt. Når raske voksne spiser renses munden samtidig for ca 1/3 bakterier. Den hypofunktionelle mund har behov for hjælp til at blive renses på slimhinderne: gane, tunge og kinder. Konklusionen er at systematisk periodontal vedligeholdelse også bør foretages hos ældre med omsorgsbehov også selvom det er svært at foretage pga logistik, kooperationsvanskelighed, plejepersonale eller økonomi.

Koricho Matsuo, Tokyo Medical and Dental University: Oral frailty and oral hypofunction

Den orale sundhed påvirker den generelle sundhed: en nedsat oral hygiejne kan give infektion og dermed påvirke den generelle sundhed og en nedsat oral funktion kan give dårlig ernæring på den måde påvirke den generelle sundhed. Oral hypofunktion hos især

ældre kan give: mundtørhed, dårlig mundhygiejne, reduceret okklusal kraft, spise/synkebesvær og alt dette kan føre til fejl- eller underernæring og dermed øge svindet af skeletmuskulatur, give nedsat fysisk aktivitet og øge hastigheden af behovet for omsorg. Når nogle af mundens funktioner nedsættes tager andre over. Et godt eksempel er mennesker uden eller med få tænder, der adspurgt til tyggefunktion svarer at de kan spise alt. Her er det ofte tungen, der "tygger". Koricho Matsuo viste flere apparater, der kan måle forskellige orale funktioner som tungetryk, mundtørhed, hygiejne, okklusal kraft, tyggefunktion og læbe-tunge bevægelse. Hans pointe var at måling kan føre til intervention.

24.08.2022 SEMINAR - Orthodontics in SCD

Orthodontic treatment in the group of patients with intellectual disabilities represents the most challenges. Many scientific studies have shown deviant dentofacial morphology, impaired oral function and high prevalence of malocclusion. The seminar discussed the barriers for proper orthodontic treatment for this group of patients including behavioral issues, uncontrolled movements, reduced cooperation and communication and prejudices (from the practitioners treating the patient), while also naming the basic requirements for delivering orthodontic treatment. When it comes to the group of patients with disabilities, the expectation of orthodontic treatment should be adjusted from ideal to "good enough" suggests **Stefan Axelsson**, specialist in orthodontics. Facilitating pre-conditions (time, knowledge, experience, stability in the dental chair), behavior management techniques, realistic treatment goals, strategic extraction of teeth, simple orthodontic appliances and multi professional dental and medical cooperation were mentioned as the strategies for orthodontic treatment for children and adolescents with disabilities. Also specialist educational programs should be further developed and integrated to prepare the future orthodontists enough skills and confidence to provide professional orthodontic treatment to this group of patients also.

[Torsdag 25.08.2022](#)

2508.2022 SEMINAR - "Understanding oral health inequalities in special care dentistry"

Av Monica Palmö, Sverige

Populations requiring special care dentistry are not only underserved but often also have increased risk factors for poor oral health. Health professionals need to realise that these risk factors are not a matter of personal choice, but that they are related to the social determinants of health i.e. the conditions which people live, learn and age. This seminar aimed to resume current knowledge with relation to the social determinants of oral health and their interaction with disability.

The first speaker – Prof. **Georgios Tsakos**, London, UK, talked about "Social determinants and vulnerable groups: the cliff-edge of oral health inequalities". The focus on health inequalities has brought forward the role of the social determinants theoretical model. The relevant research documents oral health inequalities across age groups, populations and settings, but relatively little is known about the pathways, that can help understand inequalities and even less about the policies and interventions to address them. Vulnerable groups in society have much worse oral health, representing the cliff-edge of inequalities; however, they are not equally "visible" in either the research or the policy agenda. The role of the different aspects of the social determinants model are essential to address the gap.

The second speaker – Dr **Denise Faulks**, Clermont-Ferrand, France, told us about "An exploration of the social and environmental context of adults with disability and complex medical conditions." The results of this qualitative study involving adults with disability and complex medical conditions served as a base to describe the social and environmental factors affecting the oral health of these individuals.

Persons with disability and/or with complex health conditions are disproportionately impacted by the social, societal and environmental determinants of health. Whether affected by acquired illness, developmental disability or trauma, the majority have ongoing issues with education, employment, relationships, financial independence, medical care and social attitudes, amongst other risk factors for poor oral health. The influence of these determinants will be unpicked using data from a recent qualitative study in which adults participated in in-depth interviews relating to their perceptions of the mouth and factors influencing oral health.

Finally, examples of good practice in co-design and co-production of health initiatives described that can help to break down the barriers created by social context.

Prof. **Paul Brocklehurst**, Bangor, Wales told us about that theme – “The use of co-design when developing oral health interventions or services.”. He made us remind about that understanding the challenges of both service providers and the users of these services are critical if we are too successfully implement practices to improve oral health. Co-design adopts an inductive paradigm of partnership working, positioning research as a creative enterprise that has human experience at its core.

Engagement is key and helps address the challenges related to the translation and implementation of interventions in complex organisational settings. By identifying and understanding how different stakeholders subjective experiences are shaped as they engage with the health service, it is possible to better design these services. A number of examples had been provided of how to engage and work with stakeholders using this inductive paradigm.

I will say “Many Thanks” to all of these speakers who made a very interesting day for all of us by their great knowledge and interesting presentations!

25.08.2022 SEMINAR - The airway, disability and dentistry

Av Kristoffer Emgård, NFH Sverige, övertandläkare pedodonti

Neuromuscular and neurosensory disorders, whether acquired or developmental, can affect a person’s capacity to protect the airway when swallowing. Dysphagia, aspiration and silent aspiration are all factors to be taken into account when providing dental treatment and oral hygiene measures. This seminar was address to the problems faced and the techniques that could be used to minimize the risk of aspiration. In addition, the assessment of anaesthetic risk was discussed for patients requiring dental treatment under general anaesthesia. The impact of sleep apnea was also discussed and the role of the dentist in the prevention and treatment of this condition presented. Dr. **Ria Prasad** (London UK), Dr. **Avanti Karve** and Dr. **Clare Farrell** (Sydney Australia), Dr. **Delphine Wagner** (Strasbourg France) conducted this seminar successfully and captivated the audience even though the room was warm!

25.08.2022 SEMINAR - Reaching out

Av Erik Helander, övertandläkare, specialist i Pedodonti, Folktandvården Västra Götaland

On the afternoon of august 25 an appreciated seminar was held on "reaching out i special care dentistry". Vulnerable populations throughout the world may not present spontaneously to oral health service and there might be several barriers to overcome. One of the speakers at this interesting seminar was Dr **Martha Paisi** from the University of Plymouth, United Kingdom, who talked about her research on how to improve dental care access and provision for people who experience homelessness. Dr Paisi started with enlightening the audience that homelessness is still a significant challenge, even in developed countries, and people experience homelessness have higher levels of untreated dental disease and more missing teeth than the general population. A study in London revealed that 60 percent of the participants had toothache since they become homeless, and 15 percent had pulled out their own teeth. People experiencing homelessness can have precarious living conditions making the routine of attending appointments difficult. Dr Paisi means that efforts to improve equity in access to dental care require significant change in healthcare policy and in the approach that "One size fit all" dental service model. Outreach can often help people experience homelessness by meeting them in their own environment and build positive relationships with healthcare professionals. To achieve good outreach, it is also important to educate the next generation of dental professionals to have a greater understanding of the complexity of homelessness. In Plymouth, community engagement is now an important element of the undergraduate programme at the Faculty of Medicine and Dentistry. Last, but not least, Dr Paisi stressed that dental interventions can improve a homeless person's quality of life and that an improved oral health can become an important catalyst to a wider change in many areas of life, such as improved general health, confidence, and happiness. This in turn may well contribute to finding a way out of homelessness and unemployment, and Dr Paisi also described a real case where this indeed had happened.



Dr Martha Paisi from the University of Plymouth, United Kingdom, and Erik Helander, övertandläkare, specialist i Pedodonti, Folk tandvården Västra Götaland.

Fredag 26.08.022

25.08.2022 SEMINAR - How very early intervention can improve long-term outcomes.

Av Elin Wang, tannlege, Reykjavík, Island

Natacha Linas DDS from Clermont-Ferrand in France spoke on Friday morning about how very early intervention in tooth rehabilitation can improve long term outcomes in nutrition, growth and development. Dr. Natacha Linas also spoke at the NFH conference in Reykjavik 2017 and this ongoing study is a follow up on the research she showed then. Natacha is currently a Ph-D student.

She showed how the capability of chewing was significantly decreased if 1 or more deciduous molar was extracted in young children. The bolus chewed for children with less than full dentition was compared to the bolus children with full dentition chewed (4 deciduous molars in contact).

The conclusion was that very early intervention (to do pulpectomy and fillings/steelcrowns) do have a positive influence for the childrens capability of mastication and nutrition.

An interesting result of the research was that when the rehabilitation was performed the BMI raised, and in some cases it became too high and the children became obese. That suggests the importance of having a nutritional counselling as well as tooth rehabilitation, because even if the mastication capability got better the diet was unchanged – cariogenic and unhealthy from a nutritional point of view. At least in some of the cases.

The research is ongoing and is going to include intervention and outcome for rehabilitation of children with agenesis of deciduous molars as in ectodermal dysplasia.

iADH Fellowship

Av Elin Wang, tannlege, Reykjavík, Island

The iADH Fellowship is a documentation for member in iADH who have been outstanding in their professional work, studies, educating and work within iADH. The persons with an iADH Fellowship award have a proof for their expertise and experience.

iADH had a taskforce group where people from the educational committee prepared the application form which was made on the SurveyMonkey platform. The project was launched on three online webinars which were attended by over 250 members. The application process was open from 15th January to 1st April 2022 and will be so in the beginning of the years to come. This year 54 people filled the form out and sent it in for evaluation. The applications were initially evaluated by two independent assessors who scored the applications according to agreed pro-forma. The applicants who did not succeed this time had a feedback of their evaluation in order to know the aspects to improve in future application. They can then reapply within 2 year without extra cost. The iADH Fellowship is designed to be suitable for dentist, hygienists and allied healthcare professionals each of which group has a special application form to fill out.

At the congress in Paris the first iADH Fellowships were announced. 31 persons received an iADH Fellowship award. Among these was **Stefan Axelsson**, dr. odont and specialist in orthodontics from TAKO Center in Oslo. He was the only one from any of the Nordic countries to get the iADH Fellowship award.

Hereby Bulletin wishes Stefan Axleson congratulation on the honourable iADH Fellowship award.



The first members of iADH were awarded a Fellowship celebrating excellence in Clinical Care, Research, Education , Advocacy, and iADH Community Activity.

Results from the iADH Research Competition 2022

IADH are delighted to announce the winners of the research competitions. The head judges Professor Pedro Diz Dios and Professor Bláthnaid Daly presented prizes to the delighted winners during the General Assembly at iADH Paris 2022.



Congratulations to:

BEST Basic Research (oral) – Masahiro Watanabe (Japan)

BEST Early Career (oral) – Jessica Venco (Italy)

BEST Public Health Research – **Essi Karikoski (Finland)** and Peter Schmidt (Germany)

BEST Case Report / Case Series Ignacio Camarda Rojas (Chile) and Robyn Clark (UK)

BEST Education Research – Maryani Mohamed Rohani (Malaysia)

Abstract of the study of Essi Karikoski

Karikoski E, Children's Hospital, Department of Children and Adolescents, Helsinki University and Helsinki University Hospital, Finland.

Sarkola T, Children's Hospital, Department of Children and Adolescents, Helsinki University and Helsinki University Hospital, and Minerva Foundation Institute for Medical Research, Helsinki, Finland.

Blomqvist M, Children's Hospital, Department of Oral and Maxillofacial Diseases, Helsinki University and Helsinki University Hospital, Finland.

essi.karikoski@helsinki.fi, taisto.sarkola@helsinki.fi, my.blomqvist@hus.fi

Early counselling to improve oral health behavior in major congenital heart disease – results from a randomized controlled trial

AIMS: To assess early repeat counselling for oral health behavior in a randomized controlled trial.

METHODS: All children born in Finland 1.4.2017-31.3.2020 with a) congenital heart defect (CHD) at risk for endocarditis or b) any CHD with surgical repair and a chromosomal syndrome, were offered to participate (NCT03329170). 70 children randomized 1:1 to CHD

intervention and CHD control, and a parallel group of 89 healthy children were included. In the final analysis 25 CHD intervention, 27 CHD control and 50 healthy children were included. Counselling with motivational interviewing was provided to intervention group at baseline, 6, 12, and 18 months of age. Oral health behavior was evaluated in three domains (tooth brushing, sugar intake, and dental care contact) at 24 months, and among CHD intervention also at 12 and 18 months.

RESULTS: At 24 months, teeth brushing was performed twice a day in 19/25 (76%) CHD intervention, 12/27(44%) CHD control ($p=0.026$, intervention vs control), and in 37 /50 (74%) healthy ($p=0.014$, CHD control vs healthy) children. Similarly, fluoride toothpaste was used twice a day in 19 /25(76%) CHD intervention, 9/27(33%) CHD control ($p=0.003$, intervention vs control), and in 28/50 (56%) healthy ($p=0.093$, CHD controls vs healthy) children. Electric toothbrush was used in 12/25 (48%) CHD intervention, 5/27(19%) CHD control ($p=0.038$, intervention vs control), and in 7/50 (14%) healthy ($p=0.744$, CHD control vs healthy) children. Among CHD intervention, there was a gradual improvement in tooth brushing, fluoride toothpaste and electric toothbrush use between 12 months and 24 months. Sugar drink intake was more common in CHD control vs healthy children ($p=0.029$), but similar to CHD intervention children.

There were no statistical group differences in dental care contact domain.

CONCLUSION: CHD children are at risk for poor oral health behavior. Tooth brushing habits can be improved in CHD children with early repeat counselling.

Nordiske postere som ble presentert under iADH kongressen i Paris

Outline of an Oral Care Program for Children and Adolescent with Neuropsychiatric Disabilities.

Maria Hall, dental assistant, and **Pia Dornérus**, dental assistant, Mun-H-Center, Folktandvården Västra Götaland,

LONG-TERM FOLLOW-UP OF THE DEVELOPMENT OF DENTITION AND OROFACIAL FUNCTIONS IN CHILDREN WITH BECKWITH-WIEDEMANN SYNDROME.

Gisela Vasconcelos and **Pamela Åsten**. TAKO-centre - National Resource Centre for Oral Health in Rare Disorders

Quality of teeth matters too – a possibly new symptom in MED13L syndrome

Helena Anjou, Department of Paediatric Dentistry. National Oral Disability Centre for Rare Disorders, The Institute for Postgraduate Dental Education, Jönköping, Sweden.

Unique teeth. A web-based search tool for dental health personnel, to aid in the diagnosis of rare disorders.

Ole Rasmus Theisen, BSc, DDS, **Tiril Berggren**, DDS, **Hilde Nordgarden**, DDS, MS, PhD

TAKO-centre - National Resource Centre for Oral Health in Rare Disorders. Lovisenberg Diaconal Hospital, Oslo, Norway



Outline of an Oral Care Program for Children and Adolescent with Neuropsychiatric Disabilities



Maria Hall, dental assistant
Mun-H-Center, Folkhälsöorden Västra Götaland,
Gothenburg, Sweden
Contact: maria.hall@vgregion.se



Pia Dominus, dental assistant
Mun-H-Center, Folkhälsöorden Västra Götaland,
Gothenburg, Sweden
Contact: pia.dominus@vgregion.se

Background

Mun-H-Center is a national referral resource centre for rare diseases with experience in specialist dental care for patients with neurodevelopmental disorders (NDD). Many children and adolescents need preventive dental care. Sensory hypersensitivity as well as cognitive difficulties can affect the patient's ability to cope with oral care at home and in the dental clinic. They often need a person-tailored approach and adapted treatment schemes as well as structured gradual exposure. In this patient group, it is important to establish good routines early in life so that a good oral hygiene can be maintained throughout life as well as early familiarisation to the dental care environment.

Aim

This project aims to provide a comprehensive oral care program for children and adolescents with NDD with guidelines for gradual exposure to the dental environment and treatment schemes for the dental team.

Materials and method

An extensive literature search on "NDD and dental care", "gradual exposure and anxiety", and "low arousal approach" was performed. The retrieved information was analysed by two dental nurses together with one paediatric dentist and one psychologist, all of them with long experience in working with children and adolescents with NDD. The information retrieved together with clinical experience was compiled into a written oral care program with focus on NDD for dental personnel.

Results

An oral care program was designed with background information on NDD, recommendations on environmental adaptations in the dental situation, pictorial support and preparation, guidelines for adapted gradual exposure and treatment schemes. The programme also included advice in communication and the "Low Arousal Approach".

Conclusion

Children and adolescents with NDD may need special consideration and adaptation to cooperate in the dental situation. Increasing the knowledge and providing information on person-tailored, low arousal approach and treatment strategies may facilitate the treatment planning for dental care personnel and improve the dental care and the success rate for children and adolescents with NDD.



For additional information,
use QR code, contact
Maria and Pia or visit
www.mun-h-center.se



**LONG-TERM FOLLOW-UP OF THE DEVELOPMENT OF DENTITION AND
OROFACIAL FUNCTIONS IN CHILDREN WITH BECKWITH-WIEDEMANN
SYNDROME**

100061

gisela.vasconcelos@tako.no

Gisela Vasconcelos¹, Pamela Åsten¹

¹ TAKO-centre – National Resource Centre for Oral Health in Rare Disorders



Background

Beckwith-Wiedemann syndrome (BWS) is a rare paediatric overgrowth syndrome with distinct genetic and clinical features. Clinical findings are variable and include characteristic facial appearance, macroglossia, hyperplasia, anterior abdominal wall defects and gigantism. Macroglossia is present in most of the cases.

The problems caused by the enlarged tongue include difficulties with feeding, distorted speech and drooling. The position of the teeth and lower jaw are often altered. Respiratory difficulties may occur due to tongue obstruction. The presence of hemihyperplasia may lead to asymmetric overgrowth of the head and face. Tongue reduction surgery is a treatment option.

Objectives

Describe development of dentition and orofacial functions of 8 patients with BWS from childhood to adolescence based on systematically collected data.

Methods

A Norwegian model for standardized long-term follow-up of the development of dentition, facial growth and orofacial functions was outlined by the TAKO-centre and the National Craniofacial Team in order to validate the quality of care for children and adolescents with BWS. Examinations by a specialist in orthodontics, paediatric dentist, speech and language pathologist, otolaryngologist surgeon and plastic surgeon are performed at key ages in order to identify treatment needs and to provide coordinated care.

This protocol includes follow-up of patient with BWS both with and without tongue reduction surgery.

Population and Results

All individuals in this study had macroglossia and two of them had a tongue reduction. Anterior open bite was present in all cases in the primary dentition. Dental spacing was also common. In the transition from mixed to permanent dentition a reduction of the anterior open bite was registered with dento-alveolar compensation.

The orofacial functions such as speech, chewing and swallowing also improved from childhood to adolescence in most individuals.

Primary dentition



Mixed dentition



Permanent dentition



Conclusion

This study may provide useful information for clinical guidelines and improve multiprofessional evidence based practice in Beckwith-Wiedemann syndrome.

References

- Chong J, Shuman C, Weisberg R. 2010. Beckwith-Wiedemann syndrome. *Am J Med Genet* 2010; Part C 154C:343-354.
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Unique teeth

A web-based search tool for dental health personnel, to aid in the diagnosis of rare disorders

Ole Rasmus Thelsen BSc, DDS, Tiril Berggren DDS, Hilde Nordgarden DDS, MSc, PhD
 TAKO-centre - National Resource Centre for Oral Health in Rare Disorders, Lovisenberg Diaconal Hospital, Oslo, Norway

#00100112
 oth@tako.no

Unmet need

- Dental personnel are short on time
- Rare findings may not be investigated
- Existing resources are of limited relevance for clinical dental personnel

Solution

- A web-based search tool
- Users select findings in the oral cavity and then add general signs and symptoms
- A short list of potential diagnoses to consider further is produced

Implementation

- A database of rare disorders associated with oral findings
- Limiting findings to clinically relevant and identifiable options
- Short descriptions of each diagnosis and links to further resources

Clinical implications

- Make rare diseases more accessible to dental personnel
- Make dental personnel more relevant to the medical and rare disease community
- Aid patients through timely diagnosis

Lovisenberg Diaconal Hospital
TAKO - centre

Norwegian National Advisory Unit on
RARE DISORDERS

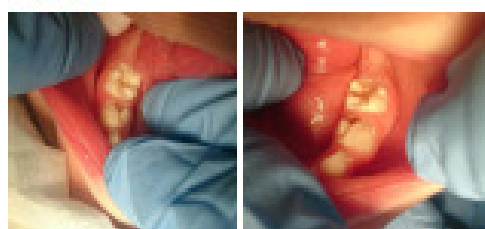
Quality of teeth matters too – a possibly new symptom in MED13L syndrome

Helena Anjou

Department of Paediatric Dentistry, National Oral Disability Centre for Rare Disorders, The Institute for Postgraduate Dental Education, Jönköping, Sweden.

INTRODUCTION

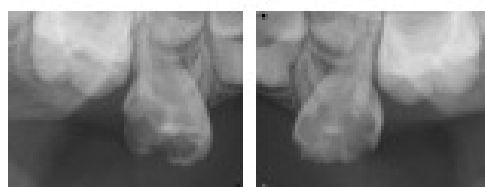
MED13L-syndrome is a rare genetic condition characterized by developmental delay, intellectual disability and minor differences in facial features. Amelogenesis imperfecta is a rare genetic developmental disorder affecting dental enamel.



The first treatment during general anesthesia.

CASE REPORT

A 2-year old girl presented with severe dental breakdown and received prompt treatment, including several extractions, under general anesthesia. Clinical appearance of the extracted teeth was more reminiscent of mineralization disorder than caries so the teeth were analysed by an oral pathologist. However, due to severe breakdown of the tooth crowns, it was impossible to diagnose any other pathology than dental caries.

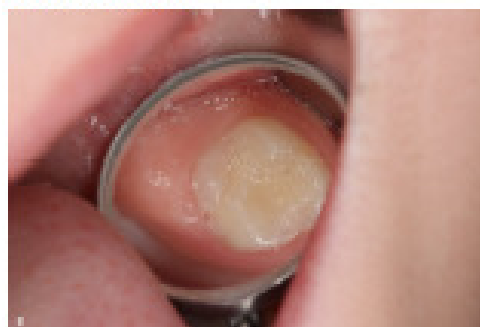


The second treatment during general anesthesia.

When the girl was four years old, two new primary teeth erupted, both with severely affected enamel. They were extracted immediately after eruption, and this time, the anatomical pathology analysis showed amelogenesis imperfecta - hypomaturation type.

Besides problems with her teeth, the girl had delayed development and a different facial appearance. After extensive clinical investigations at

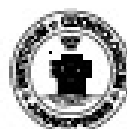
the Child Habilitation Centre and genetic examination, she was diagnosed with MED13L-syndrome at seven years of age. Amelogenesis imperfecta has not earlier been described in connection with this mutation and may be a newly discovered symptom in MED13L-syndrome. Preventive dental treatment with frequent visits since early age, has resulted in good oral hygiene and remaining primary and erupting permanent teeth are caries free, despite general enamel hypomineralization. All teeth have clinical signs of amelogenesis imperfecta, but so far without tooth breakdown.



The first erupting molar.

CONCLUSION

This report highlights the importance of perseverance when searching for explanations to clinical problems. It also shows that, even if amelogenesis imperfecta is not a known part of this particular syndrome, the dentist has a role in the multidisciplinary diagnostic team of rare disorders. Finally, it illustrates the necessity of intense and targeted preventive measures to stop negative outcomes. Quality of both care and teeth matters!



Odontologiska Institutionen
Region Jönköping AB

The Institute for Postgraduate Dental Education,
Region Jönköping County, Sweden

ARTWORK



Artwork created during the congress with contribution from the congress delegates.

IADH has established a new partnership with Oral B

At the opening ceremony of iADH2022 in Paris a partnership was announced between iADH and Oral B. Together they plan to address inequitable oral health outcomes for people with disabilities through research, education, innovation and advocacy.

Read more on www.businesswire.com/news/home/20220823005621/en/Oral-B%20Announces-its-Partnership-with-the-iADH-International-Association-of-Disability-and-Oral-Health-to-Help-Make-Oral-Care-More-Accessible-and-for-All



Benjamin Binot, Oral Care Senior Vice President at Procter & Gamble and Prof Alison Dougall, President of the International Association of Disability and Oral Health (iADH).
Credit: Djibrann Hass

SVENSKA SEKSJONEN www.nfh-sverige.se

Ordförande

Monica Palmö, Council-member i IADH

Specialisttandvården, Orofacial medicin, Blekingesjukhuset, 371 85 Karlskrona

mo.palm@telia.com

FINSKA SEKSJONEN

Ordförande, puheenjohtaja

Aija Kalmari

aija.kalmari@fimnet.fi

NORSKA SEKSJONEN

Leder, Council-member i IADH

Stefan Axelsson, spesialist i kjeveortopedi, dr.odont.

TAKO-senteret, Lovisenberg Diakonale Sykehus, Lovisenberggata 17, 0456 Oslo, Norge

Tfn. direkte +47 23 22 59 25 Tfn. resepsjon +47 23 22 59 49

stefan.axelsson@tako.no

DANSKA SEKSJONEN

Formand og Rådsmedlem i IADH

Tandlæge Torben L. Gasseholm

tandpleje, Nyborg

tlg@nyborg.dk

ISLANDSKA SEKSJONEN

Formand og Council Member i IADH

Tandlæge Elin Svarrer Wang

Vegmúli 2, IS-108 Reykjavík

Tel: +354 588 2140

elinw@hotmail.com

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Ansvarig utgivare: Stefan Axelsson, ordförande NFH, Norge

Redaktionskommitté: Monica Palmö, Sverige, Torben Gasseholm, Danmark, Stefan Axelsson, Norge, Elin Svarrer Wang, Island och Aija Kalmari, Finland.