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EPA INTERVIEW
Interviewer. Congratulations on being elected to EPA Council. Please tell me something about yourself.

Simon. Well, I’m what we call a Consultant Paediatrician in Community Child Health in the UK which means I provide care to children and young people outside hospital settings.

Interviewer. Why did you choose that as a career?

Simon. I trained in paediatrics, nearly had a career in neonatology, and while I enjoyed acute care and saving lives I realised that it was the care for children with long-term conditions and disabilities and their families, that was most in need of improvement.

Interviewer. Could you expand on what you mean?

Simon. When I first started as a consultant paediatrician, I was referred children by general practitioners and the expectation was that I would see them in 20-30 minutes, diagnose their conditions and then either refer back to the general practitioner or review them again, probably every six months. Occasionally, I would get to know a family in more depth and realise the impacts of living with a long-term condition might have on the child, their parents and any siblings. I then began to realise how few support services that were for these families.

Interviewer. So what did you do next?

Simon. I thought I would start with the most complex children and chose those with non-malignant life-threatening conditions. I researched the associated prevalence and morbidity of these conditions—which was a world first and found they were four times more prevalent than previously thought. Unsurprisingly there was significant morbidity for parents, siblings and whole families and so set up a children’s palliative care service known as the Lifetime Service, run predominantly by community children's nurses and clinical psychologists with the necessary skills, to support these families. The service was positively evaluated and received a number of awards.
Simon Lenton

Interviewer. What happened next?

Simon. The Lifetime Service model was adopted by the six Diana Nursing Teams, which were established as a memorial following the death of Princess Diana and then the Government made a £35 million investment to role the model out across England. I then worked with a charity now known as "Together for Short Lives" to develop a multiagency care pathway approach to help the planning, delivery and improvement of the services. This included a matrix to aid end of life planning, now known as the "Wishes Document" for advanced care planning for children. The intention is that children with life-threatening conditions have a regularly reviewed care plan that addresses the likely issues facing the child and family, including end of life care when that is imminent.

Interviewer. My guess is that you would like to see better palliative care develop across Europe?

Simon. The simple answer would be yes, but I am more interested in learning how other paediatricians and services are tackling similar problems across Europe so that I can learn from the best and then implement those ideas locally. For example, locally we now ventilate children at home, who previously lived their lives on paediatric intensive care or hospital wards. This enables them to grow up at home with their parents, go to school and have more normal lives. I would be very interested to know how other paediatricians are responding to this challenge of technology dependent children.

Interviewer. What do you see as the major challenges facing the development of children's services in Europe?

Simon. I recently chaired an expert group to examine child friendly health care on behalf of the Council of Europe. Throughout Europe are similar issues - increasing demands on services, decreasing investment in services, often significant variations in the outcomes of similar services both within and between different countries, and the gene-
ral feeling is that often services both within health and between different agencies are not well integrated meaning that the experience from the perspective of children and families is that services are disjointed and fragmented.

**Interviewer.** Tell me more about this child friendly health care initiative.

**Simon.** First we acknowledged the problems facing health services to children and families. We then examined the UN Convention on the Rights of the Child and extracted the relevant principles that relate to service delivery (rather than individual care-recognising that there is a degree of overlap).

The three key principles that have practical implications are prevention, participation and provision based on pathways. If I may expand briefly:

1. Prevention includes protection from hazards that have the potential to cause harm and promotion of exposure to assets that have positive effects in terms of promoting well-being and resilience. In some ways they are the two sides of the prevention coin reflecting pathogenesis and salutogenesis.

2. Participation - we need to give children, young people and their families a greater voice in “the system” meaning greater involvement with individual decision-making, a clear role in service provision-as they are the ones that experience the healthcare process and finally a voice in the policy making and resource allocation parts of the system so that the issues that are important to today’s children are reflected in future service development.

3. Provision based on pathways. To achieve good outcomes all the parts of a pathway need to be in place and working well together, coupled with key measurements along the way, with associated quality improvement initiatives to rectify any deficiencies found, as the outcome is only as good as the weakest link in the pathway.

Child friendly health care brings all these elements together into a practical framework that nations can adopt and adapt to their own local conditions as a starting point to improve the integration and experience of services to children and families. 


Whilst written for the health service it is equally applicable to all agencies that contribute to better outcomes.
Interviewer. How was that received?

Simon. Remarkably well. I spent two days with 47 civil servants representing all the nations in Europe going through the document line by line and ironing out elements of the text which may not be politically acceptable to health ministers. Having reached a consensus the child friendly health care approach was endorsed by Ministers across Europe in the Declaration of Lisbon in 2011.

Interviewer. What has happened since then?

Simon. It's difficult for me to know, the Council of Europe was reorganised and is now less involved with health and healthcare issues, so there has been no formal rollout strategy or an evaluation of implementation. In the UK I have taken the concepts of child friendly health care and adapted them for the current UK National Health Service structures, which have recently been radically reformed in England. I am calling this a "Family Friendly Framework" for the improvement of services to families.

Interviewer. If I gave you a magic wand and one wish, what would it be?

Simon. We all live on a small planet, that does not have unlimited resources, and perpetual economic growth is an ecological impossibility. We are already seeing the impact of human induced global climate change, growing inequalities within and between nations and the inevitable population migrations that follow. My wish would be for meaningful international cooperation to tackle the fundamental underlying economic problems, in order to achieve realistic sustainable development for the benefit of future generations of children.
Planning for this important international scientific meeting is now well underway and we hope that you will join us at the 7th European Congress in May 2015 for what will be
EPA-UNEPSA COUNCIL MEETING  
(Thursday, January 23, 2014 - Istanbul)

Members present:  
Leyla Namazova-Baranova (President)  
Manuel Moya (Vice-President)  
Julije Mestrovic (Vice-President)  
Massimo Pettoello-Mantovani (Secretary General)  
Jochen Ehrich (Treasurer)  
Simon Lenton (Councillor)  
Fügen Çullu Çokuğraş (Councillor)

an innovative and interactive educational programme. The meeting, which is being held in the centre of Florence, one of the most beautiful and cultural cities in Italy, will bring together almost 2000 paediatricians and other child health professionals from Europe and the rest of the world to share learning, expertise and ideas.

The programme for the congress, which is the highlight of the activities of the European Paediatric Association, the Union of National European Paediatric Societies and Associations (EPA/UNEPSA) is being developed by the EuroPaediatrics2015 Scientific Committee. This 7th biennial meeting will have an innovative format, with a mixture of plenary presentations by international child health experts and guideline sessions led by the European specialist societies which will give general paediatricians an opportunity to bring themselves up to date with the best evidence-based practice. The theme of sharing good practice will be continued in the more interactive personal practice sessions where leaders in their fields will present their approaches to the management of important paediatric conditions.

There will also be an opportunity to listen to debates, view posters and participate in workshops and discussions on topics of relevance to the wider aspects of the health and wellbeing of children and
young people worldwide such as diversity, equity and children’s rights. The conference will also be accredited with the relevant European educational programmes so delegates will be able to register for CME/CPD points.

Outside of the scientific programme, there is a social programme which includes a cocktail party and gala dinner and many opportunities for informal social exchanges. We particularly hope that the Europaediatrics2015 will be an occasion for those in the early stages of their careers to meet new colleagues and forge lasting friendships across Europe as well as for others colleagues to renew old friendships. When the scientific programme is over for the day, the setting for the Congress in the Fortezza da Basso in centre of Florence offers opportunities for delegates to visit world-renowned museums and art galleries or just to stroll the streets and take in the views and the history in the city which was the cradle of the Renaissance.

Further details of the programme will be announced on the EPA website www.epa-unepsa.org and there will be an early-bird rate for delegates registering early.
EPA-UNEPSA NEWSLETTER
As Chair of the Scientific Committee of EuroPaediatrics 2015 I would like to welcome you to Florence 13-16 May 2015. Florence is one of the most beautiful cities in the world with a unique artistic history, a wonderful Mediterranean climate and Italian food and style!

The international airport is 4 km from the city centre. There are 378 hotels to choose from, most within walking distance of the city centre Conference venue, the museums, the restaurants and the railway station.

We plan to make this conference as interactive as possible, responsive to the needs of practising paediatricians and to reflect previous delegate feedback.
We want the conference to help your paediatric practice when you return to work in your country the following week.

For example, we aim to have ‘Clinical Guidelines’ Sessions presenting national or international Guidelines led by European Specialist Societies and of interest to general paediatricians across Europe. There will also be ‘Personal Practice’ Sessions and ‘Sub-Specialty’ Workshops in a number of paediatric fields.

Attendees at Personal Practice Sessions will receive extra Continuing Medical Education Credits and all participating delegates will receive a Certificate of Attendance per session. Delegates who attend 3 Personal Practice sessions will receive a Diploma instead of separate Certificates.

Depending on delegate numbers, we will choose an appropriate size of room and indeed may run popular sessions more than once over the 4 days of the meeting. We are looking at the possibility of simultaneous translation for the most popular sessions.

The theme of the conference will be ‘Learning across Borders and Languages’, a kind of educational ‘Medicine sans Frontières’:

- Apprendimento delle Lingue attraverso le Frontiere e
- Apprendre à travers les Frontières et les Langues
- Über Grenzen und Sprachen hinaus Lernen
- Aprendizaje a través de las Fronteras e Idiomas
- Обучение через Границы и Языках

There will also be plenary lectures, debates, ‘hot topics’ sessions, satellite symposia and themed free communication sessions with Faculty feedback for less senior presenters.

We will be calling for abstract submissions for these free communication and poster sessions. The book of abstracts with all the accepted abstracts will be published as a supplement to The Journal of Pediatrics.

Training opportunities will include a media training sessions on “How to become a good presenter” and “How to write an abstract”.

Of course we have plans too for an opening ceremony, welcome buffet and cultural program.

I hope you agree that an interactive format and the involvement of leading European Specialist Societies will contribute greatly to an attractive programme in Florence.
We hope you will accept our invitation to attend EuroPaediatrics 2015.

Professor Terence Stephenson
BSc, BM, BCh, DM, FRCP, FRCPCH, FRACP, FRCPI, FHKAP
Nuffield Professor of Child Health, Institute of Child Health, University College London
Chair, UK Academy of Medical Royal Colleges
Past President, Royal College of Paediatrics and Child Health
What is social paediatrics?

I would like to introduce EPA members to the field of social paediatrics (SP). Many of you will practice SP every day whilst for others, it is akin to social work. I would like to put this straight!

To me social paediatrics is at the core of what we all do as general paediatricians – treat the child, family and environment as a single entity. This entails embracing prevention with cure, mental health with physical health, integrating school with the home environment and giving serious consideration to the social determinants of health.

So for example, a ‘social’ paediatrician (or general paediatrician with a social orientation, a term I prefer) would ensure that when a child presents with otitis, his immunisation status, growth and speech development are also checked; that the developmental level and hearing are assessed in a four year old presenting with oppositional behaviour; that an eight year old complaining of persistent abdominal pain is asked about parental relationships and whether he is being bullied at school; and for a child of 8 presenting with obesity, the social background and availability and
costs of healthy food for the family are investigated before jumping into dietary advice. This kind of approach has for long been appropriate and well used by wise paediatricians of all subspecialties. The ‘social’ paediatrician would go further by working with other disciplines (including social work and school teachers) to ensure that the management plan really works. In a world when social conditions have a very major impact on children’s lives, a socially orientated approach is not only necessary, but mandatory.

**ISSOP**

The International Society for Social Pediatrics and Child Health was founded in 1978 as ESSOP, the European Society. Its aims were education, teaching and research in relation to social paediatrics, together with advocacy to improve children’s health. Advocacy has always been a central part of ISSOP’s work – since children’s health is severely hampered by factors in society such as poverty and inequalities, marketing of junk food aimed at children, smoking, pollution from motor traffic, climate change and many more. In a globalised society, paediatricians need to stand together with other pressure groups to remove the external pressures which hamper children’s health, development and wellbeing.

Originally most European countries were represented in ESSOP, the most active being Sweden, UK, Netherlands, Greece, Spain, Hungary, Turkey, Switzerland and Iceland. From the early days, there were members from outside Europe – mainly the Anglophone countries Canada, USA, Australia and New Zealand. In 2012 it was decided by members that ESSOP should become international and extend its remit globally – which was a major challenge, since global health issues are much wider than those we encounter in Europe. ISSOP would need to get to grips with malnutrition, HIV/AIDS, female genital mutilation and child labour – as well as recruiting members from Africa, South America and Asia. Sounds an impossible task!

A solution came in the form of CHILD2015, an internet forum within the family of HIFA – Health information for all be the year 2015 - www.HIFA2015.org/CHILD2015

CHILD2015 aims to meet the information and learning needs of those responsible for the care of children in low income countries; its remit includes children’s rights to health and healthcare and the social determinants of health. Recent topics on the forum include female genital mutilation, consent to vaccination, corporal punishment of children and corporate pressure on breast feeding.

I encourage all EPA members to join CHILD2015, which has a membership of nearly 3000 child health professionals from all over the world – from Africa to Geneva and Philippines to the USA.

**Some key themes of ISSOP**

Key themes of ISSOP are child rights, the social determinants of health, the use of the school as a health setting, and using epidemiological data to influence health service direction. Evidence-based approaches are seen as essential in determining new methods of prevention and promotion. Currently ISSOP has position papers on inequalities in health, breastfeeding, migrant children in the EU and a further one in draft on sponsorship of paediatricians by the Baby Feeding Industry.
These can be found on the ISSOP website, www.issop.org.

ISSOP hosts an annual meeting in a different country each year and in the coming June it will be held in Gothenburg, Sweden on the topic of Measurement of Health – a child public health perspective. Further details are on the ISSOP website.

A summer school is also held regularly in Croatia, and the next will be in Turkey in April 2015 on vaccination.

ISSOP has a working group on child rights training which is working with a US group to develop an on-line training course on child rights in health care.

**Social paediatrics globally**

What are the issues for social paediatrics globally? Among the topics which have been discussed on CHILD2015 are whether immunisation should be mandatory; the influence of the Baby Feeding Industry on rates of breastfeeding; the role of ‘Baby Boxes’ in management of abandoned babies; and ways of reducing the prevalence of female genital mutilation. ISSOP also recognises that there are many issues in common between low income and high income countries, for example – child abuse, the exploitation of children, and the lack of attention being paid to teenage health. Quite a big agenda, and first we need to find strong partners to work with. We hope and expect that the EPA can be one of these.

**Linking with the EPA**

How can ISSOP work more closely with the EPA to our mutual benefit? ISSOP members were pleased to read the challenging words of the new EPA President Professor Leyla Namazova in the last e-bulletin in relation to advocacy on inequalities in health and the quality of life across Europe. She further emphasised that her one wish was to see the UN Convention on the Rights of the Child implemented across Europe and the world. We entirely agree and will be happy to help with these noble objectives!

Tony Waterston
ISSOP Executive Committee member, 6.5.14
Pediatricians and other health professionals all over Europe are demanding more training in adolescent health. EPA-UNEPSA has recognised this growing interest by including adolescent health in its regular congresses and the forthcoming Europediatrics in Florence in 2015 will be no exception.

Pediatricians who want more need look no further than the EuTEACH network (European Teaching and Training in Effective Adolescent Care and Health – see www.euteach.com), which is at the forefront of helping develop training opportunities in adolescent health in Europe.

EuTEACH is a network of pediatricians, public health physicians and GPs that was set up in 1999 to enable better training in adolescent health in Europe. Based in Lausanne, Switzerland, and led by Prof. Pierre-André Michaud, EuTEACH has developed a training curriculum for adolescent health, run a highly successful
Summer School in Lausanne as well as in many different European countries, and also undertakes a range of training consultancies in adolescent health for organisations such as WHO, Unicef and UNFPA. A Russian ‘branch’ of EuTEACH was set up in 1999 under the leadership of Prof. Alexander Kulikoff in partnership with Unicef.

**EuTEACH Curriculum**

The EuTEACH website is a wonderful resource for any pediatrician searching for training materials in the health of adolescents. EuTEACH modules on the website cross the spectrum of clinical medicine through to public health. The core pediatric issues are very well represented, including puberty and adolescent development, communication with young people, chronic conditions, consent and confidentiality in adolescence and common medical problems affecting young people. The curriculum also contains a range of other modules that are highly relevant for pediatricians, from mental health, sexual health and contraception, eating disorders and vaccinations through to making your service more youth-friendly to advocacy on behalf of young people.

Each module is a training resource, providing a framework to enable you to teach sessions on adolescent health, from the most basic to quite advanced. Interactive teaching methods are at the heart of each module. Modules also contain a range of example powerpoint slides, links to other web resources and for training videos.

Summer School For those who want to develop their knowledge or skills in working with adolescents, the EuTEACH Summer School runs each year in Lausanne. Until now, there have been 12 Summer schools including one advanced course.

The objectives of the EuTEACH Summer School are:

- To improve the quality of health care and preventive services delivered to adolescents, using the best available evidence
- To develop more effective skills for adolescent health teaching and advocacy

The participants come from all over the world including Europe, Egypt, Kazakhstan, New Zealand, United States, Madagascar, and Thailand. Most participants are physicians and nurses, but also psychologists, social workers and other professionals with both clinical and public health experiences participate.

EuTEACH facilitators use interactive teaching methods including group discussions, mini lectures, interactive exercises role play and simulated patients. Participants work in groups and former summer school participants function as ‘table leaders’ and facilitate exercises, group work and discussions.
The program includes

- Adolescent development
- Chronic conditions and transition
- Mental health
- Substance use
- Communication skills and interviewing the adolescent (with simulated patients)
- Youth friendly health services
- Public health and advocacy

For the last two years, participants have been able to choose two to three chosen modules regarding

- Eating disorders
- Common medical problems
- Cultural issues
- Legal issues and ethics
- Sexual health
- Epidemiology and research
- Family influences and dynamics
- Exploratory behavior

The social program includes get together party, wine tasting and gala dinner at the rooftop restaurant at the university hospital (CHUV). Many of the participants arrange their own excursions in Lausanne and to nearby cities e.g. Montreux.

The participants have in general been very satisfied. The mean rating of the course (on a scale from 1 [very poor] to 10 [excellent] is > 9, and almost all would recommend the course to colleagues.

Consultancies on adolescent health  A growing aspect of EuTEACH’s work has been…. (ANNE on consultancies and mandates)
EuTEACH works closely with the European arm of the International Association of Adolescent Health (IAAH) – with the next European meeting in Paris in June 2014. See http://www.iaah-paris2014.org

This link between EuTEACH and IAAH has been very useful for the development of adolescent medicine in different countries. For example in Denmark, the Center of Adolescent Medicine started at Rigshospitalet, University of Copenhagen in 2008. The mission of CAM is to improve conditions for young people with critical illness and chronic conditions. The work of the multidisciplinary team is directed towards staff through training, supervision and development of transition programs and towards young patients through the work of the social educators for long-term hospitalized adolescents, the youth club HR BERG, young people friendly environment, information material and outpatient clinics for young people.

Staff training is based on the EuTEACH modules and the members of the CAM team have participated in the EuTEACH Summer School including the TOT (teaching the teachers) module in the 2011 advanced course. The flag ship of staff training in CAM is the Youth Ambassador training program. Youth Ambassadors are nurses with special interest, training and experience of working with young patients. The training program includes nine whole days of interactive training sessions and discussions, a small project at the local departments and continuous networking after the theoretical program. CAM has arranged conferences and lectures inviting the experienced teachers from the EuTEACH network to promote the development of adolescent medicine and advocate for youth friendly health services in Denmark.
In the last EPA Newsletter, we shared with you the American Academy of Pediatrics (AAP) child health agenda and current activities supporting these priorities. As we move into the last quarter of 2014, the AAP looks forward to our continued relationship and collaboration with the EAP. We would like to take this opportunity to share with you our recent commitments and priorities for global child health.

In 2012, 6.6 million children died before their 5th birthday from not only treatable but completely preventable diseases. As a national pediatric society, the AAP will not accept this statistic. The United States and its partners have committed to ending preventable child deaths. The AAP supports this commitment and advocates for high-quality, high-impact maternal, newborn and child health interventions that save lives, promote healthy development, and strengthen children, families and communities.

Sustained progress is especially possible when applying an integrated strategy that links key interventions across the continuum of care, from mothers and newborns to children and adolescents. Interventions should engage clinicians and other stakeholders to support their ability to strengthen their health care systems while also addressing health equity within countries.
The AAP works with the U.S. government, other partners, and through the International Pediatric Association (IPA) to ensure that global health programs are funded and children everywhere have access to the care they need to survive and live healthy lives. Our advocacy is informed by our global programs and our members' international work.

During December 2013 and the first quarter of 2014 AAP worked to identify strengths and gaps in the global health advocacy landscape, criteria for evaluating global health policy and advocacy opportunities, and a set of initial priorities. The overarching theme of the priorities is to increase access to healthcare for children around the world. Within this theme, we highlight the need for low-tech, low-cost/high-impact interventions, sustainability through primary care system engagement and strengthening, including clinicians as participants and educators, equity within countries, and a spectrum of care from prevention through treatment.

**Saving Newborn Lives**

- A skilled birth attendant in the 24 hours preceding and following childbirth
- Immediate essential newborn care; prevention and management of infections; prevent and management of preterm/low-birth weight newborns; and newborn screening and management
- Good nutrition, including exclusive breastfeeding during the first 6 months

**Keeping Children Healthy**

- Universal access to immunizations and the strengthening of routine immunization systems; advocating for polio eradication, measles and rubella elimination, development of new vaccines, and support for the GAVI Alliance
- Interventions that target malaria and other infectious diseases, and promote good nutrition and safe water and hygiene
- The prevention and management of non-communicable diseases, including tobacco smoke exposure, along with injury prevention and attention to mental health and children with special health care needs
- Support for and coordination around country plans that engage clinicians and other stakeholders

**Promoting Early Childhood Development**
• Promoting supportive environments for all children to avoid toxic stress and contribute to healthy brain development

• Good nutrition for the mother and child to ensure healthy growth and development

• Preventing and treating non-communicable diseases and injuries in children and adolescents by strengthening primary, secondary and tertiary health care, promoting healthy lifestyles and obesity prevention, and encouraging smoking prevention and cessation (including addressing smoke inhalation from indoor cook stoves). While also bringing attention to mental health, the special needs of children with disabilities, and education and awareness-raising around injury prevention.

• Addressing the needs of children in disaster preparedness and response

As the global community gears-up for the post-2015 health agenda, the AAP has been active in contributing to country plans and United Nations’ consultation processes in order to make sure the pediatrician voice is heard in the development of the new goals. Our priorities will guide our contribution to the post-2015 health agenda. The AAP is supportive of stronger goals focusing on non-communicable diseases, inequalities, and universal health care. Specifically, we will be making new commitments to ensure that children and adolescents are included in the non-communicable diseases discussion and agenda. We also advocate for country specific goals which hold developed nations accountable for meeting strict child health goals in the same way that developing countries will.
In May, 2014, AAP made a new commitment to the Every Newborn Action Plan (ENAP) in the form of a new multi-national partnership. The Helping 100,000 Babies Survive and Thrive initiative is a new partnership between the AAP and the pediatric societies of India, Ethiopia, and Nigeria. Along with the Survive and Thrive Global Development Alliance (GDA) partners and in-country stakeholders, the Helping 100,000 Babies Survive and Thrive initiative partners’ vision is, “To support the Every Newborn Action Plan - a world in which there are no preventable deaths of newborns and stillbirths, every birth celebrated, and women, babies, and children survive and thrive and reach their full potential.” The work under the new initiative includes four educational train-the-trainer modules which directly address preventable newborn deaths. With implementation of skills learned in the modules, birth attendants will be better equipped in supporting newborns to survive and thrive, especially those newborns born too small, too early, or unable to breathe. This commitment was announced in June 2014 at the USAID Acting on the Call meeting in Washington, DC, which noted the two year anniversary of the Call to Action for Child Survival in 2012.
At the United Nations General Assembly in New York City in September, the AAP, NCD Child, UNICEF, and the IPA will sponsor a side-meeting to highlight the importance of the non-communicable disease child agenda. If your national society or health ministry plans to be at UNGA and you are interested in participating, please contact us immediately.

The 2014 AAP National Conference and Exhibition will feature multiple sessions on the post-2015 health agenda including a plenary session given by Hans Rosling of Sweden who is a professor and medical doctor and co-founder and chairman of Gapminder Foundation. The AAP Section on International Child Health will devote its all-day educational program during the National Conference to the post-2015 health agenda. Additionally, the National Conference and Exhibition will have a four day track of sessions which will have simultaneous translation in Spanish-English.

For additional information about the AAP and its global activities please visit www.aapglobal.org or contact us at aapglobal@aap.org.

For additional information about the AAP and its global activities please visit www.aapglobal.org or contact us at aapglobal@aap.org.
THE PROBLEM: INEQUALITIES IN ACCESS TO AND QUALITY OF PAEDIATRIC DIABETES CARE

Despite guidelines and consensus statements related to approaches, targets and therapies, there remains huge variation across Europe in the quantity and quality of diabetes-related research and in care available for people with diabetes. This variability is a consequence of many factors, the most significant being the social and cultural differences among countries, differences in clinical governance, and lack of structured networks of interested parties with commonly agreed goals. Also to this day, shortcomings in paediatric diabetes management occur; despite modern treatment options more than 50% of children with diabetes develop complications or co-morbidities 12 years after diagnosis. In addition, inequalities in levels of and access to specialized multidisciplinary diabetes care and education continue to exist across the EU. Furthermore, the European DIAMAP project pointed out that diabetes research would be greatly enhanced if the clinical research community itself could drive a collaborative initiative. The need for registries of patients, networks of specialist researchers, access to bio-banks and human biological material and the need for more standardised treatment guidelines have repeatedly been mentioned as roadblocks in the European diabetes research landscape.

SWEET: THE KEY TO BETTER CARE FOR CHILDREN AND ADOLESCENTS WITH DIABETES
THE SOLUTION: A SWEET COR NETWORK

Since the inequalities in access to and quality of paediatric diabetes care are mainly due to the underlying differences in systems, the most straightforward solution is the creation of a network of paediatric diabetes centres across Europe, connected through common objectives and standards.

THE SWEET-PROJECT: HOW IT ALL STARTED

SWEET e.V. began as an EU-funded project (2008-2011), called 'the SWEET-project'. SWEET stands for: ‘Better control in Pediatric and Adolescent diabetes: Working to create CEnTres of Reference’. The main purpose of this project was to improve secondary prevention, diagnosis and control of T1DM and T2DM diabetes in children and adolescents by supporting the development of Centres of Reference (CoR’s) for paediatric and adolescent diabetes services across the EU. The main result of the SWEET-project has been the development of a Paediatric Diabetes Toolbox which includes recommendations for:

1) minimum treatment and care;
2) patient education programmes;
3) training programmes for health professionals.

In addition, minimum criteria for CoR’s for paediatric and adolescent diabetes have been developed. During the SWEET-project, 13 centres were part of the SWEET CoR network. In all these centres, a multidisciplinary team consisting of at least one paediatric diabetologist, one diabetes nurse/educator, one dietitian, psychologist and social worker are working together in order to provide not only specialised care for children and adolescents with diabetes, but also individualised health care professional education for these patients. In addition, all these centres have a close collaboration with one another (the network) and use a common data collection system to evaluate and compare health(care) data which are used for research.
purposes as well. Towards the end of the SWEET-project (April 2011), it became obvious for the SWEET consortium that there remained much more work to be done: To this day shortcomings in diabetes management still occur and inequalities in levels of and access to specialized multidisciplinary diabetes care and education continue to exist across the EU. For this purpose the SWEET-project network has been transformed into a legal entity, SWEET e.V., as a registered charity under the guidance of the International Society for Pediatric and Adolescent Diabetes (ISPAD).

THE COR NETWORK – VISION AND GOALS OF SWEET E.V.

SWEET e.V. seeks to expand the implementation of these reference centres so that all European healthcare professionals and patients have access to innovative paediatric-specific diabetes care. In addition, the electronic health database (SWEETBASE) and the SWEET website are being reviewed to enable the use of secured portals both for healthcare professionals and, in the future, for patients.

BENEFITS OF (BECOMING A MEMBER OF) THE SWEET COR NETWORK:

ACCESS TO STANDARDISED, PAEDIATRIC-SPECIFIC DIABETES CARE AND TREATMENT GUIDELINES BOTH NATIONALLY AND WORLDWIDE:

Differences between guidelines may influence surveillance and quality of care in paediatric diabetes within Europe. We evaluated national treatment guidelines for the care of children with diabetes across Europe. Although most countries recommend the ISPAD Clinical Practice Consensus Guidelines (CPCG), these guidelines are far from implemented across Europe. Main reasons are language barriers and the necessity to adjust the guidelines to the European context. SWEET e.V. has aimed therefore to endorse the further translation and contextualisation of the ISPAD CPCG to render it accessible to all healthcare professionals. Once implemented on a European wide level, benchmarking of carefully defined quality of care and quality of life indicators will allow us to improve these guidelines on a regular basis ensuring an evidence-based care for all children.

ACCESS TO STANDARDISED PATIENT EDUCATION PROGRAMMES AND PAEDIATRIC TRAINING PROGRAMMES FOR HEALTHCARE PROFESSIONALS:

Since diabetes management requires far-reaching lifestyle changes, it is indispensable that quality-assured and age-appropriate education is delivered to the patient, the family and other caretakers, not only at disease onset but also for following-up on through adulthood. Furthermore, structured curricula, experienced and trained educators and education are integral parts of long-term care. However, only very few countries have published and implemented a structured curriculum lead and evaluated programmes for different age-groups and caretakers. In addition, a huge variety of creative tools for educating children of different age-groups and their parents are available – but most of them are not linked to a structured education programme. SWEET aims therefore to harmonise and integra-
te these education materials into holistic, structured, quality-assured national education programmes. A comprehensive European diabetes educational toolbox has been published.

Also healthcare professional training shows great diversity and lack of standardisation, making it a complex task to have transferable education concepts and qualifications across European borders. SWEET supports therefore a standardised, accredited approach to the training and continuing professional development of health care professionals and the Paediatric Diabetes Multidisciplinary Team (MDT): Recommendations for the training of the MDT has been developed and published.

ACCESS TO A COMMON PATIENT-DATA HANDLING, INTERNATIONAL BENCHMARKING, QUALITY CIRCLES AND RESEARCH PROJECTS:

Since appropriate, safe and reliable data collection is essential for longitudinal evaluation, follow-up of clinical outcome parameters and comparison of data within and between patients and centres, SWEET has developed an electronic database system, SWEETBASE. On the basis of standardised electronic health records, and treatment modalities are collected, anonymised and submitted to the common database. An expert group, consisting of a statistician, an IT specialist and several diabetes specialists, discusses the unmasked comparable data, identifies gaps, deficits and inequalities between centres in different EU Member States and develops solutions for reducing these inequalities. The reporting structure allows for monitoring of ongoing changes at centre, national and EU levels and can as such also be used for research purposes. Finally, current therapy recommendations can be adapted on basis of the ongoing comparisons and evaluations as well as successful approaches and techniques can be disseminated.

Currently, 27 CoR’s from 19 different countries are connected to the database through an online platform. Twice a year, all these centres submit data for longitudinal health analysis. The number of patients and patient visits has continuously increased from 2006 onwards, currently including over 10.000 patients and nearly 130.000 patient-visits.

The SWEET network: Centres of Reference (red pins), Collaborative Centres (yellow pins), Applying Centres (green pins)

SWEET e.V. - DREAMS AND MISSIONS FOR THE NEAR FUTURE:

The SWEET network will generate leverage for raising paediatric diabetes-related issues, both on a national and European level.

The next aims are to receive more transparency in the cost of diabetes-specific care and to improve the quality of life of children with diabetes across Europe. Therefore SWEET is planning an extension of the eHealth platform that will allow analysing diabetes-specific health economic data.
In addition, patients will have an ability to log on to their own secure patient portal to complete outcomes assessments, receive relevant reminders and education material, as well as communicate with their local paediatric diabetes treatment centres. On this basis, SWEET also hopes to increase the efficacy of the prevention of long-term complications.

Finally, the SWEET dream is to make the newest approaches and most successful programmes available for all healthcare professionals across Europe, ensuring as such equal accessibility to up-to-date and highly qualified diabetes care for young diabetes patients.

To become part of SWEET, for additional information and references, please contact SWEET e.V. at:
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In the last decades the great improvement in the health of children in the Croatia was achieved. The better general living standard, the vaccination and the possibility of treatment of numerous diseases improved children’s health status and saved many lives. The similar success wasn't achieved in the field of children's injuries, although some positive
changes could be noticed. After the first year of life, during all childhood up to 18 years, the leading cause of children deaths are injuries.

The disability among children is also close connected with injuries. The injuries have the impact in developing of psychological disturbances as depression and PTSD, too. The social health of community is affected by frequent accidents, the demographic lost are significant. The whole society has a huge economic lost mainly in the health sector but also in other sectors. The injury prevention is one of the most important priorities in the health promotion and protection of children's health. In 2005 started the project funded by The Fogarty International Center of the National Institutes of Health, USA. The main partners were The University of Iowa College of Public Health, USA and the Andrija Stampar School of Public Health, Medical School, Zagreb, Croatia. The Croatian Society for Pediatrics supports all project’s activities from the first days. The Croatian Ministry of health and UNICEF office in Croatia supported different interventions launched by project. The aim of the project was research followed by public health intervention in the field of child accidents- safety promotion/injury prevention. The project offered wide possibilities of research in the homeland country as well as in the USA through different kinds of training opportunities. Ten professionals from Croatia attended the education in the USA. In the wide frame of Trauma project since 2007 till the end of this, 2013, year in Croatia is going on the Croatian Ministry of Science project: Safety promotion and injury prevention for pre-school children (108-1081871-1895; project leader: Aida Mujkić). Hypothesis of the project was that public health education of parents and additional education of professionals about injury prevention and safety promotion lead to decrease in child mortality and hospital morbidity among young children. The research about knowledge, attitudes and behavior of parents and medical stuff: primary pediatricians, family physicians, gynecologists, community nurses was performed followed by interventions which included: production of the educational package consisted of the booklet, leaflets and so called “meter” and educational workshops (one course of continuing medical education for physicians and four regional workshops for community nurses). Comparing the data from 1995 with the data from 2011 we see the difference in the total number of casualties (age 0-19 years) because of injuries among children in Croatia which dropped from 291 cases in 1995 to 78 in 2011. But analyzing data according to the age group of the children it is evident that the decline happened in the pre-school population and that the school population and adolescents represent the challenge for the future work.

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The Russian Federation is a country with one of the most effective systems of pediatric health care, achieved considerable success in reducing infant, child and maternal mortality, as well as in the prevention, diagnosis and treatment of infectious and non-infectious diseases in children, continues its consistent steps to other States on achievement of the Millennium Development Goals. Joint in 2010 to the implementation of the Muskoka Initiative on maternal, newborn and children under 5 health, Russia has focused its efforts primarily on the transfer of health services experiences to the countries with developing economies. For this purpose during the last three years the Government of the Russian Federation is funding a number of projects on supplementary training for pediatricians, neonatologists, anaesthetists and other pediatric specialists from Asia, Africa and Latin America.
nal Forums, organized annually on the basis of leading Russian medical institutions in the field of pediatrics and obstetrics, became a highly popular platform for exchanging views and working up further recommendations to improve pediatric, obstetric and gynecologic care in the countries-participants.

In compliance with the objectives 15-17 April 2014 in Moscow in the main Federal pediatric institution - the Scientific Center of Children's Health of the Federal Agency for scientific organizations in Russia - the 3rd International Forum “Reducing Child Mortality - the Russian experience of universal pediatric coverage for child population as an instrument for achieving Millenium Development Goals” took place.

Greetings to participants of the Forum were sent by Chairman of the Federation Council Federal Assembly of the Russian Federation Valentina Matvienko, Chairman of the State Duma Sergey Narishkin, Foreign Mini-

Forum united pediatricians and health officials from 21 countries: more than 130 foreign participants from Azerbaijan, Angola, Armenia, Belarus, Botswana, Vietnam, Germany, Zimbabwe, Kazakhstan, Kyrgyzstan, Moldova, Mongolia, Nicaragua, USA, Tajikistan, Uzbekistan, France, Ethiopia, as well as more than 100 Russian Forum participants from Moscow, St. Petersburg and other Russian regions. The lec-
tures were presented on the most pressing issues of the organization of pediatric health care and education for professionals in the field of pediatrics, it was shown the international pediatric systems diversity with the description of strengths and weaknesses of each of them (Germany, Spain, Russia, USA, France, Japan), World health Organization representatives reported about progress in achieving Millennium Development Goals. EPA leadership representatives focused their attention on the modern pediatric and social problems: pediatrician’s role in the protection of child rights (professor L. Namazova-Baranova), national and International Professional Associations in implementing the MDGs (professor J. Ehrich) and new aspects of the neonatal screening (professor M. Moya).

The unique potentialities of the newly constructed highly specialized simulating-training center on the basis of the Scientific Center of Children’s Health have been demonstrated to the Forum delegates. The specialized training courses for pediatricians from countries-participants would be organized in 2014-2015 in this specialized simulating-training center. The Final Statement has been adopted on the results of the Forum.
In Turkey there are approximately 9000 pediatricians distributed in a huge area. In 1929 - in the early days of the Turkish Republic - a few clear-sighted pediatricians founded the ‘Turkish Pediatric Association’ in order to interact and support each other for a better healthcare service for the children. Since the early days the number of members expanded, the meetings, symposiums and yearly congresses attracted many specialists all around Turkey and more international links are strengthened for the child care advocacy.

Nevertheless there was a part of the pediatricians who were a bit neglected all around the world. The ‘Younger Ones’. The 1st year residents trying to figure out what this specialty is all about; the senior residents struggling between providing the expected performance while preparing for the exams, writing their thesis and the recently specialized pediatricians whose carrier expectancies were about making a difference in science instead of moving in a vicious circle- bringing out some disappointments and demotivation.
When the board of the Turkish Pediatric Association looked closer and talked with some of their residents, it was seen that a huge amount of the colleagues (all together over 1200 residents) in the early stages of this path had difficulties in their working life. Some lucky ones were able to take active part in the meetings, congresses etc. but many younger colleagues were feeling isolated, even depressed at the very beginning of their career.

Hence, at the end of 2011 Turkish Pediatric Association has organized a subdivision called “The Young Pediatricians” focusing on the pediatrics residents and young specialists in every aspect.

First, a questionnaire to assess and point out the problems pediatrics residents are dealing with was prepared. A high percentage of the pediatricians took part in it and resulting from this questionnaire the most important issues were;

1) Lack of education during the residency (due to different types of Institutions with varied number of professors and subspecialties)

2) Unclear scope of the responsibilities and requirements of pediatric residency

3) Working conditions and personal safety (continued night shifts throughout the day=33 hours of service, accelerating violence towards the medical staff etc.)

4) Inappropriate and unequal income for residents (also differing incomes from one institution to another for the same effort)

5) Problems of the foreign residents (no income, same responsibilities, no guarantee for a secure job later on etc.)

6) Compulsory state service (after passing all the exams, an approx. 500 days of compulsory service in a state hospital anywhere in Turkey is required to gain the diploma – even to those who don’t want to work in a state institution afterwards.)

The questionnaire exposed that many young colleagues were not content with their career (choice/environment of the specialty). Sadly to the question of "if you would resign what would you do afterwards?" 25 %said -I would choose a different lighter specialty such as dermatology, physiotherapy etc.

68% expressed that they would take the state university exam after all these years to study something extremely different (such as law, architecture etc.)!

The topics concerning the employee rights and working conditions are naturally difficult to deal with because of the need of legislative challenges. On that matter, Turkish Pediatric Association works together with the Turkish Medical Association proposing issue changes on medical education and work conditions to the government.
The questionnaire unraveled that there are also many issues where small but instant changes can be made.

Where we can’t rectify the disorganized institutional pediatric education of residents we could do something on our own. These young residents at the beginning of their career need more support and motivation on their scope and feeling isolated is the first step where one can begin to make some changes. After all these results some action was compulsory:

✓ Communication:

“The Young Pediatricians” presented all their data in the

National Congress of the Turkish Pediatric Association’ in 2012 and held an interactive symposium with lots of brain storming for solutions dealing all those problems. Some task-sharing for issues like education, working conditions, communication is done among them.

To begin with, to almost every other resident or younger colleague received an e-mail explaining the scopes. An e-mail group is launched and the Facebook group of Turkish Pediatric Association is activated for easy communication.

In the newsletter of the society every three months there are columns written by the young pediatricians about their own problems and also photo galleries and interesting case presentations.

✓ Education:

In 2012-2013 we’ve arranged meetings for:

a) interactive case presentations -every first Friday of the month-,
b) daily courses of quick review of subspecialties (after the related case presentations)

c) long-term courses – e.g. 4 Sundays in 2 months – on “how to plan a study”, “analyzing medical statistical data’s”, “how to write a paper”, “issues on medical ethics” and “how to make an impressive presentation”.
All meetings took place at the central office of the Turkish Pediatric Association in Istanbul. All the participants were either resident in general pediatrics/pediatric subspecialties or specialists, who recently begun with their career. 6 case presentation evenings, 6 courses each with 30-45 participants were completed at the beginning of the summer 2013. The participation rates were high and the feedbacks were great. Colleagues from other cities were able to watch the presentations online later on. Requests for more meetings in different locations in Turkey have motivated us to keep on. This year (2013-2014) meetings in all 7 different regions of Turkey is started, and also broadcasted online to reach more pediatricians.

In conclusion, Young Pediatricians have just begun to communicate more among each other in our country for support, motivation and improvement of the conditions of pediatricians but there are many more things to be done. Especially in Europe, where active and effective organizations such as EPA/UNEPSA are connecting specialists throughout the continent. We, the younger ones from Turkey are looking forward to collaborate with our colleagues to make changes for the pediatrics practices in Europe.
Dear Colleagues,

I would like to draw your attention to the possibility of participating as collaborative partners to the Inherited Neurometabolic Diseases (InNerMed) Project and invite you to join a growing network. InNerMeD has been funded by the Executive Agency for Health & Consumers (DG-SANCO) under the Second Programme of Community action in the field of Health, 2008-2013 to be the first European Network on neurometabolic diseases.

InNerMeD's goal is to create a network of information targeted on diagnosis and treatment of inherited Neurometabolic Diseases (iNMDs) based on the collection and exchange of validated information among scientific community, health professionals, patients, patient associations and all interested stakeholders.

The project aims to increase and harmonise the current knowledge on iNMDs, at the benefit of patients and their families. In fact, InNerMed aims at helping the patients and the families affected by rare diseases by understanding the meaning of the rare disease which they suffer from, providing all validated information needed (from the description of the disease to the legislation of patient’s right) and avoiding the confusion that is created by a random fishing of news from the web. The network will also favour biomedical research, straightening research capacities and fostering innovative therapeutic tools derived from the recent scientific advancements based on biomarkers use and personalised approaches.

InNerMeD is a very ambitious program. With the proper network of experts and the coordination of
the information that will be uploaded in the artificial-intelligence information platform which is under
development, we think that we can achieve our goals.

InNerMeD Information Network is coordinated by
BRAINS FOR BRAIN FOUNDATION, ONLUS
c/o Dipartimento di Pediatria SalusPueri
Via Giustiniani 3 I-35128 Padova (Italy )
www.brains4brain.eu
This is why we would need your help as expert in the field of the neurometabolic diseases.
We would greatly appreciate if you could provide the attached questionnaire which is designed to
achieve all the information necessary to implement the network on a pilot group of disorders we
thought might be useful to test our strategy and the results of the projects.
Please do not hesitate to contact me for any information you may need, we value your help and
really appreciate your collaboration.
Best wishes

Maurizio Scarpa
For more information please contact me at Maurizio.scarpa@brains4brain.eu
Direct link to the website:
Direct link to the questionnaire:
CoPE (Copenhagen Pediatric Emergency) is an iOS- and Android-app developed with the intention of assisting the clinician (pediatrician/anesthetist/intensive care physician/emergency physician) in the preparation of acute lifesaving treatment of children in pre-, or in-hospital setting.

The app is developed at Department of Anaesthesia, Centre of Head and Orthopaedics, Copenhagen University Hospital Rigshospitalet, Denmark.

We offer 50 members of EPA/UNEPSA a free copy of the app (iOS only).

SAVE THE DATE
“Diagnosing, analyzing and treating Robin sequence”

A CONSENSUS MEETING

Save the date:
31 October, 1 November 2014
Utrecht The Netherlands

We are looking forward to your participation in this exciting project
Albania
Albanian Paediatric Society

Armenia
Armenian Association of Paediatrics

Austria
Oesterrechische Gesellschaft fur Kinder-und Jugendheilkunde (OEGKJ)

Azerbaijan
Azerbaijan Pediatric Society

Belgium
Societe Belge de Pédiatrie/Belgische Vereinigung voor Kindergeneeskunde

Bosnia and Herzegovina
Paediatric Society of Bosnia and Herzegovina

Bulgaria
Bulgarian Paediatric Association

Croatia
Croatian Paediatric Society

Czech Republic
Czech National Paediatric Society

Denmark
Dansk Paediatrisk Selskab

Estonia
Estonian Paediatric Association

Finland
Finnish Paediatric Society

France
Société Française de Pédiatrie

Georgia
Georgian Paediatric Association

Germany
Deutsche Gesellschaft für Kinder- und Jugendmedizin (DGKJ)

Greece
Hellenic Paediatric Society

Hungary
Hungarian Paediatric Association

Ireland
Royal College of Physicians of Ireland/Faculty of Paediatrics

Israel
Israeli Paediatric Association

Italy
Società Italiana di Pediatría

Società Italiana di Ricerca Pediatría

Italian Federation of Primary Care Pediatricians

Latvia
Latvijas Pediatriu Asociācija

Lithuania
Lithuanian Paediatric Society

Luxembourg
Société Luxembourgeoise de Pédiatrie

Macedonia
Paediatric Society of Macedonia

Moldova
Moldovan Paediatric Society

The Netherlands
Nederlandse Vereniging voor Kindergeneeskunde

Poland
Polskie Towarzystwo Pediatryczne

Portugal
Sociedade Portuguesa de Pediatria
Romania
Societatea Romana de Pediatrie

Russia
The Union of Paediatricians of Russia

Serbia and Montenegro
Paediatric Association of Serbia and Montenegro

Slovakia
Slovenska Paediatricka Spolocnost

Slovenia
Slovenian Paediatric Society

Spain
Asociación Española de Pediatría

Sweden
Svenska Barnläkarföreningen

Switzerland
Société Suisse de Pédiatrie/Schweizerische Gesellschaft für Padiatrie

Turkey
Türk Pediatri Kurumu

Ukraine
Ukraine Paediatric Association

United Kingdom
Royal College of Paediatrics and Child Health
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7th Europaediatrics
13-16 May 2015, Florence, Italy

Members and Affiliated Societies’ Meetings

XVII Congress of Pediatricians of Russia with International Participation “Actual Problems of Pediatrics”
14-16 February 2014, Moscow, Russia

110th Annual Meeting of the German Society for Pediatric and Adolescent Medicine (DGKJ)
11-14 September 2014, Leipzig, Germany

14th National Congress of the Portuguese Society of Pediatrics
3-5 October 2014, Porto, Portugal

58th Turkish National Pediatrics Congress jointly held with the XIV Turkish Speaking Countries Congress of Pediatrics (UNPSTR), the 35th UMEMPS Congress and the 13th Turkish National Pediatric Nurses Congress
22-26 October 2014, Belek-Antalya, Turkey

Other Paediatric Meetings

European Respiratory Society (ERS) Annual Congress 2014
6-10 September 2014, Munich, Germany

European Research Conference on Paediatric Neurology - EPNS Research Meeting 2014
11-14 September 2014, Bucharest, Romania

53rd European Society for Paediatric Endocrinology (ESPE) Annual Meeting
18-20 September 2014, Dublin, Ireland

The AAP National Conference & Exhibition (AAP Experience)
11-14 October 2014, San Diego, USA

5th Congress of the European Academy of Paediatric Societies (EAPS 2014)
17-21 October 2014, Barcelona, Spain

Excellence in Paediatrics 2014
3-6 December 2014, Dubai, United Arab Emirates

European Paediatric Neurology Society Congress 2015
27-30 May 2015, Vienna, Austria

54th European Society for Paediatric Endocrinology (ESPE) Annual Meeting
1-3 October 2015, Barcelona, Spain