



Bridges for  
CHILD

## CONFERENCE BOOKLET

# Bridges for CHILD

Combating Health Inequalities in Life-threatening Diseases

November 17-18, 2011    Vienna, Austria  
Hotel Hilton Danube



Co-financed from the EU Health Programme 2008-2013



Executive  
Agency for  
Health and  
Consumers





# WELCOME

Dear Participants,

Welcome to Vienna and the 1<sup>st</sup> International Bridges for CHILD –Conference. We are looking forward to your personal contribution to this cross-border effort at counteracting health inequalities.

What is special about this event is the great diversity of people we have gathered and their many-faceted involvement in the care of very sick children.

We are confident that you will not hesitate to let us share your experiences in this matter and we hope that you will leave the conference with many new ideas and impulses.

This conference is an experiment which is a step in the right direction and as you all know every journey starts with a first step.

We wish you a fruitful stay in Vienna!



**Ulrike Salzer-Muhar**

Division of Paediatric Cardiology  
Dept. of Paediatrics & Adolescent Medicine  
Vienna Medical University



**Christoph Aufricht**

Division of Paediatric Nephrology  
Dept. of Paediatrics & Adolescent Medicine  
Vienna Medical University

Dear Participants,

As Ulrike Salzer-Muhar so aptly put it: even a long journey starts with the first step. So let me go back to the very first initiative which was at the root of this conference. In my many decades as a paediatrician and Head of the Department of Paediatrics and Adolescent Medicine at the Medical University of Vienna, I have seen children of all ages with all types of illnesses from benign to very serious and across all paediatric subspecialties. These children came from Austria as well as from abroad. So I could witness the still disquieting inequalities in paediatric health care that decide the fate of sick children. Of course I realized that something concrete had to be done. But what? In many talks we developed the idea of this conference, which is also benefitting from the help of the Head of the Division of Paediatric Surgery, Professor Dr. Ernst Horcher, and the Medical Director of the St. Anna Hospital, Professor Georg Mann. I am very keen to see the ideas, suggestions and visions you all come up with and I wish you a successful conference.



**Arnold Pollak**

Head of the Department of Paediatrics and Adolescent Medicine  
Medical University of Vienna

Dear Participants,

Today we strive very hard for comprehensive care in all medical fields. Regarding children it is therefore of paramount importance that our effort starts with family planning, genetic counselling and the unborn child and is followed by continuous monitoring and care until adulthood.

The field of Paediatrics includes care for all children. This encompasses somatic disorders as well as mental disturbances and also specific developmental challenges including learning disabilities and social behaviour. With relatively low costs the healthy and successful life of a whole generation can be assured.

Therefore successful comprehensive medical care for children is fundamental for the future of our society.



**Reinhard Krepler**

Medical Director of the Vienna General Hospital

Dear Participants, Ladies and Gentlemen,

Children are our future. This phrase - albeit much-quoted - is very true. In consequence, Paediatric Medicine is an investment in the future. Only recently, the Medical University of Vienna has constituted a big Paediatric Centre for Children, which now also includes the St. Anna Hospital.

A child's illness always needs to be seen within the wider context of the society in which he or she lives. This applies to the children living in our big multicultural city in the centre of Europe as well as to those living in South-Eastern Europe. To reduce health inequalities in children is without doubt a highly valuable goal and a human right. By promoting and actively supporting that goal the Medical University of Vienna assumes its social responsibility.

This conference takes our activities beyond the walls of our university and out into the European Union. I am sure that this very diverse meeting will produce numerous suggestions and visions.



**Wolfgang Schütz**

Rector of the Medical University of Vienna



## PROGRAMME (as per Nov 15, 2011)

### Thursday, November 17, 2011

09:00 Registration opens

13:00 Welcome Coffee

14:00 - 14:15 **Welcome**

Conference Chairs:  
Ulrike Salzer-Muhar and Christoph Aufricht  
Moderator: Jonas Nordquist

14:15 - 15:45 **Plenary Session 1**  
**Where do we come from?**

10 speakers from various countries will briefly shed light on different aspects of inequalities in the treatment of children suffering from life-threatening diseases

15:45 - 16:15 Coffee Break

16:15 - 17:45 **Round Table Session 1**  
**Explore the present situation**

18:15 - 18:45 Welcome Drinks

18:45 - 19:45 **Opening Ceremony**

Moderation: Christoph Aufricht and Ulrike Salzer-Muhar

*Toccata - V. Malich \**

Prof. Dr. Arnold Pollak, Head of the Department of Paediatrics and Adolescent Medicine, Medical University of Vienna

*Choral Prelude - J. Derbenko\**

Prof. Dr. Reinhard Krepler, Medical Director of the General Hospital Vienna

*Sonata in d-minor - D. Scarlatti\**

Prof. Dr. Wolfgang Schütz, Rector, Medical University of Vienna  
MR Dr. Magdalena Arrouas, representative of Dr. Alois Stöger,  
Austrian Minister of Health

*Tango & Waltz – Improvisations based on A. Piazzolla\**

*\* performed by Nikolas Lazic, who was born in Vienna in 1992 and started to play the accordion at the age of six. He holds a Bachelor of Music from the Gustav-Mahler-Conservatorium in Vienna and is winner of several international prizes and awards for Accordion.*

19:45 **Dinner in Hotel Restaurant**

## Friday, November 18, 2011

- 09:00 - 09:30 **Plenary Session 2**  
**Introduction of the situation in Austria**  
Speakers:  
Veronika Wolschlager, Federal Ministry of Health, Austria  
Lena Eschenbach, medical student
- 09:30 - 10:30 **Round Table Session 2**  
**Create ideal futures**
- 10:30 - 11:00 Coffee break
- 11:00 - 12:10 **Round Table Session 3**  
**Identify common ground on overall vision**
- 12:10 – 12:15 Comfort Break
- 12:15 - 13:15 **Round Table Session 4**  
**Approaches and proposals for solutions**
- 13:15 - 14:30 Lunch          Continuing discussions
- 14:30 - 14:45 **Plenary Session 3**  
**Decision making in CHILD scenarios**  
Speaker: Peter Pokieser, Medical University of Vienna
- 14:45 - 15:15 **Round Table Session 5**  
**Concrete actions for a possible task force and final vision**
- 15:15 – 15:45 **Summary and introduction of open space discussions**
- 15:45 – 16:00 Coffee Break
- 16:00 – 17:30 **Open Space** (co-moderated by Jonas Nordquist and Thomas Schumacher)  
**Discussions of open questions, pre-defined and focus topics**  
Networking and exchange in special interest groups
- 17:30 - 18:00 **Summary of open space discussions and closing remarks**
- 19:30            **Dinner in Hotel Restaurant**

## Saturday, November 19, 2011

- 08:00 - 10:00 **Networking breakfast** Open space for discussion



## PLENUM – Presentations (as per Nov 15, 2011)

### Nov 17, 2011

- Economic gradients and care of congenital heart disease across Europe (A. Szatmari, H)
- Congenital heart disease in the Republic of Kosovo (R. Bejiqi, RKS)
- Cross border lung transplantation- a best practice model? (L. Kovacs, H)
- Underdiagnosed chronic renal disease (M. Gafencu, RO)
- Hematopoietic stem cell transplantation in the Republic of Serbia (D. Janic, RS)
- The parents´ view- what we all have in common (H. Nock, G)
- How could children with rare diseases get the medicines they need? (G. Fischer, A)
- The European insurances and the directive on patients´ rights to cross-border health care (F. Terwey, G)
- Patients´ pathways - what does the child need? (S. Lenton, UK)
- Diversity of paediatric health care across Europe (J. Ehrich, G)

### Nov 18, 2011

- Paediatric health in Austria - Strategies developed from an interdisciplinary dialogue (V. Wolschlager, A)
- Becoming a medical doctor... (L. Eschenbach, G)
- Clinical decision-making in CHILD scenarios. (P. Pokieser, A)



## ROUND TABLES (as per Nov 15, 2011)

1. How to treat children with congenital heart disease under adverse economic conditions? (Republic of Kosovo) (*Group leader: R. Gitter*)
2. How to achieve accountability in a new cardiac centre? (Romania, Sarajevo) (*Group leader: A. Szatmari / H. Nock*)
3. What is needed to ensure optimal care of children and adolescents before and after cross-border lung transplantation?(Hungary) (*Group leader: Z. Szepfalusi*)
4. How to organize care pathways in cross-border solid organ /bone marrow transplantation? (*Group leader: A. Zuckermann / G. Mann*)
5. What have universities to contribute to the reduction of health-care inequalities in European Paediatric Medicine? (*Group leader: H. Verhaaren*)
6. How to structure care pathways in life-threatening/life-limiting disease in local and cross-border health care? (*Group leader: S. Lenton*)
7. How could larger and smaller centres cooperate in the best interest of the child in cross-border health care? (*Group leader: F. Casey*)
8. How to transform the directive on patients` rights in cross-border health care into reality - economic gradients, medical indications and codes of conduct? (*Group leader: E. Horcher*)

Eventually additional round tables will be constituted on demand on site.





## WHO IS WHO – Presenters, group leaders & moderators



**Ramush Bejqi**  
University Clinical Center of Kosova  
Republic of Kosovo



**Frank Casey**  
Royal Belfast Hospital for Sick Children, Belfast  
Northern Ireland



**Jochen Ehrich**  
Children's Hospital, Hannover Medical School  
Germany



**Lena Eschenbach**  
Vienna Medical University  
Germany



**Gerald Fischer**  
Pulmonary Hypertension Association Austria and Europe  
Austria



**Mihai Gafencu**  
University of Medicine/Emergency Children's Hospital Timisoara  
Romania



**Roland Gitter**  
Children's heart centre, Linz  
Austria



**Ernst Horcher**

Medical University of Vienna, Department of Paediatric Surgery  
Austria



**Dragana Janic**

University Children's Hospital Belgrade  
Serbia



**Lajos Kovacs**

Semmelweis University Budapest  
Hungary



**Simon Lenton**

National Health House  
United Kingdom



**Georg Mann**

St. Anna Children's Hospital  
Austria



**Hermine Nock**

Bundesverband Herzranke Kinder & European Congenital Heart  
Disease Organisation  
Germany



**Jonas Nordquist**

Medical Case Centre, Karolinska Institute  
Sweden



**Peter Pokieser**

Medical University of Vienna, Medical Media Services  
Austria



**Thomas Schumacher**

osb international  
Germany



**Andras Szatmari**

Hungarian Institute of Cardiology  
Hungary



**Zsolt Szeffalusi**

Medical University of Vienna, Department of Pediatrics and Adolescent  
Medicine  
Austria



**Franz Terwey**

European Social Insurance Platform (ESIP)  
Belgium



**Henri Verhaaren**

Ghent University, Belgium & University Hospital  
Belgium



**Veronika Wolschlager**

Federal Ministry of Health  
Austria



**Zuckermann Andreas**

Medical University of Vienna, Department of Cardiac Surgery  
Austria



## ***PARTICIPANTS (as per Nov 15, 2011)***

Ferid Agani, Prishtine (Kosova)

Petra Ales, Ljubljana (Slovenia)

Magdalena Arrouas, Vienna (Austria)

Christoph Aufricht, Vienna (Austria)

Naim Bardiqi, Prishtine (Kosova)

Ramush Bejiqi, Prishtine (Kosova)

Muhamet Berisha, Prishtine (Kosova)

Barbara Brzaj, Zagreb (Croatia)

Maya Campbell, London (United Kingdom)

Frank Casey, Belfast (Northern Ireland)

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Daniela Voda, Brasov (Romania)

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Andreas Zuckermann, Vienna (Austria)



## POTENTIAL FOR IMPROVEMENT

### List of inequalities, needs and deficiencies

**The list quotes the inequalities, needs and deficiencies named by the conference participants in the “mini questionnaires” (prior to the conference):**

- A refocusing of EU regional-assistance and health-care spending to support reimbursement for cross-border health care for paediatric high-end tertiary care in major organ diseases. This would involve cross-border health care at the south-eastern border regions of the EU where welfare and economic “gradients” exist between various EU-countries.
- Accepting children with complex heart diseases for local or cross-border treatment.
- Accepting children with congenital heart disease and syndromes for local or cross-border treatment.
- Access to academic medical advice in life-threatening reversible diseases.
- Access to expensive diagnostic modalities and treatment, as for example HSCT or new drugs.
- Access to heart surgery for children in Poland.
- Access to non-governmental, non-profit organisations internationally for health care.
- Access to transplantation.
- Addressing the issues of poverty and life opportunities.
- After-treatment of children in their home country after transplantation in Austria or any other country.
- Allocated government budget for medical care is too small in Eastern European countries compared to Western Europe. The Romanian Ministry of health should allocate an increased budget for the improved equipment of medical institutions and training of highly qualified medical personnel rather than spending much money on sending children to medical institutions abroad for treatment. Development of research depends equally on existing infrastructure and budget.
- As the economic conditions in South Eastern Europe improve, health-care for critically ill neonates and infants with congenital heart disease should also benefit from that overall improvement.
- Aspects of quality of life: rehabilitation, sports, insurance, ...
- Better coordination of existing support services.
- Centres of excellence (surgery) should be established for specific diseases and be accessible for all European citizens.
- Complex care for children with cystic fibrosis.
- Corruption in health-care systems should be reduced.
- Currently the main problem in haematology and oncology lies with bone marrow transplants. Unfortunately conditions and diagnostic procedures for adequate monitoring of transplanted patients are inadequate.
- Develop awareness and education among Croatian citizens concerning the need for early detection of CHD (congenital heart disease) and provide appropriate support and timely treatment for children.
- Differences in access to treatment in Western-Eastern Europe.
- Different costs and funding models in Europe.
- Disease-specific networking & communication, e.g. video-conferences ...




- Drug reimbursement levels vary in different EU countries.
- Economic differences.
- Education.
- Emergency care.
- Employment.
- Equal standards needed.
- European citizens should have free access to the best available health services in Europe and not face any restrictions and limitations based on their nationality.
- Evaluation of accessibility to adequate medical treatment within developing eastern countries for different economic and ethnic subgroups.
- Every possible therapy should be available at no cost in Europe. For example: no prostanoids are available in Hungary and many other countries.
- Focus on orphan diseases.
- Health-care providers from eastern countries leave the country due to disproportionately low salaries. As a consequence medical paediatric institutions lack personnel. It should represent a priority for the Romanian Ministry of Health.
- Health inequalities in the therapy of major organ diseases/failures.
- Health insurance and national health programmes in emerging countries.
- Healthcare in foreign countries.
- Healthcare instruction of parents during pregnancy.
- Heart-lung support therapy.
- Home care.
- How should we treat the cases of children with CHD which are refused by Romanian hospitals? Usually they are sent home and wait to die.
- How to spread knowledge and expertise to other countries where there is no medical care system/infrastructure.
- In my view one of the biggest privileges of Austria is the comprehensive basic insurance coverage and its medical provisions and it is up to us to try and support the buildup of similar structures for those less privileged in other countries.
- Income-dependant paediatric healthcare.
- Inequalities (or unnecessary variations) in the safety and outcomes of treatment provided to children with life-threatening conditions.
- Inequalities across Europe do not result only from differences in the economical potential of the countries, but also from the disinterest of health authorities/governments and unwillingness to acknowledge the problems.
- Inequalities in education and training (need for twinning programmes).
- Inequalities in the education of medical students.
- Inequalities of national reimbursement systems of therapies.
- Inequality in access to health.
- Inequality of access to high quality paediatric cardiology and paediatric cardiac surgical services across European countries.
- Inequality, when access to interdisciplinary evaluation is needed.
- Inequality, when people want to learn about prevention.
- Influence of socio-economic status on individual health.
- Insecure medical employment.
- Insufficient budget.
- Insufficient paediatric rehabilitation programs after heart surgery in Lithuania.
- Intervention surgery for children with congenital heart disease.

- Lack of access to surgical services and medication in new, candidate and west Balkan countries.
- Lack of approved drugs for children.
- Lack of money in various healthcare systems.
- Lack of registries of patient outcomes (mortality and morbidity) across Europe.
- Lack of specialists.
- Lack of structured services for young adults who have grown up with congenital heart disease in many countries across Europe.
- Leukaemia (ALL, AML, MOS, CML).
- Matters of facilities for the transport of sick children.
- More public health activities for children.
- Oncology.
- Ongoing health-care instruction of parents during infancy.
- Organ transplantation inequalities due to different legal frameworks.
- Paediatric cardiac surgery.
- Paediatric congenital heart problems do not get sufficient attention or financing in Lithuania.
- Quality of hospital care.
- Raise funds for essential medical equipment and apparatus for the early diagnosis of CHD children (ultrasound etc.) because doctors need state-of-the-art contemporary instruments for better diagnoses.
- Research work concerning paediatric drugs.
- Right heart catheterization in studies with children should not be repeated every 3 months. 6 to 9 months would be the goal.
- Sickle cell disease, immune-deficiencies.
- Standardization of the education of paediatricians within the EU.
- The absence in Romania of a children's poison emergency centre with adequate analytical facilities.
- The access to lung transplantations for children in Poland.
- The clinical management of cystic fibrosis in Poland.
- The lack of a proper communication between doctors and parents or other persons involved.
- The lack of twinning programmes to support children who are seriously ill.
- The pharma industry is not motivated to search for innovative therapies for children with rare diseases.
- Therapy for severely neurologically affected children.
- To point out basic children's needs and special needs (kindergarden, therapies for disabled children, ...)
- Treating children with chromosomal anomalies and heart diseases.
- Underfunding of paediatric healthcare.
- Undiagnosed children with chronic renal disease or other rare diseases.
- We do not have suitable rehabilitation facilities for paediatric heart surgery patients in Lithuania.
- We need to explain paediatric cardiology issues to government and society in order to create better facilities, get financial and moral support.




## MINI CVs – Conference holders

|   |  |   |
|---|--|---|
| <b>ULRIKE SALZER-MUHAR</b>  |  |  <b>MEDICAL<br/>UNIVERSITY<br/>OF VIENNA</b> |
| <b>Workplace</b>  | Department of Paediatrics and Adolescent Medicine, Medical University of Vienna, Austria   |   |
| <b>Current responsibilities</b>   | Associate Professor of Paediatrics at the Vienna Medical University<br>Senior Staff Physician in the Division of Paediatric Cardiology<br>Head of the Core Unit for Medical Education and Training in Paediatrics.   |   |
| <b>INVOLVEMENT IN CHILD HEALTH CARE</b>   |  |   |
| <p>Paediatrician and Paediatric Cardiologist. Formerly Acting Head of the Division of Paediatric Cardiology in Vienna. Recognized expert in paediatric, congenital and fetal echocardiography. Currently focusing on functional neonatal echocardiography.</p> <p>Over 30 years´ of teaching experience. Lectured in courses run by the European Society of Cardiology and the Association for Paediatric and Congenital Cardiology (AEPC) in various countries as well as in hospitals in Romania, Siberia and Kazakhstan.</p> <p>Head of the Core Unit for Medical Education and Training in Paediatrics since 2011.</p>                          |  |   |
| <b>PARTICULAR INTERESTING DETAILS OF CURRENT AND PAST WORK AND /OR STUDIES</b>  |  |   |
| <p>Participated in humanitarian activities in the field of Paediatric Cardiology and General Paediatrics. Has been running an electronic outpatient service for Eastern European families to facilitate cross border health care in Paediatrics since 2009.</p> <p>More than 20 years of active participation in the „Psychosocial Care from Fetus to Adult“ Working Group of the AEPC, an interdisciplinary and multi-professional group of experts, patients and parents. Chairperson from 1996-2002. This experience provided me with insight into the numerous problems faced by a child and a family living with congenital heart disease.</p> |  |   |
| <b>WHAT MAKES ME KEEN ON PARTICIPATING IN THIS CONFERENCE?</b>  |  |   |
| Through my activities across Europe I became highly aware of inequalities in child care- not only in the subspecialty of Paediatric Cardiology but also in other Paediatric subspecialties and I decided that something has to be done about it.  |  |   |
| <b>TWO HEALTH INEQUALITIES THAT SHOULD BE DEALT WITH URGENTLY:</b>  |  |   |
| 1   | As the economic conditions in South Eastern Europe improve, health-care for critically ill neonates and infants with congenital heart disease should also benefit from that overall improvement.   |   |
| 2   | A refocusing of EU regional-assistance and health-care spending to support reimbursement for cross-border health care for paediatric high-end tertiary care in major organ diseases. This would involve cross-border health care at the south-eastern border regions of the EU where welfare and economic “gradients” exist between the various involved EU-countries. |   |
| <b>ASPECTS WHERE I OR MY ORGANIZATION COULD MAKE A USEFUL CONTRIBUTION TO ONE OR MORE ASPECTS OF CHILD HEALTH INEQUALITIES?</b>   |  |   |
| <p>I personally strive to make maximum use of my network to reduce inequalities wherever I can, also through my work in the AEPC.</p> <p>This is supported by my employer, the Vienna Medical University.</p>   |  |   |



## MINI CVs – Conference holders

|  |   |   |
|--|---|---|
| <b>CHRISTOPH AUFRICHT</b>  |   |  <b>MEDICAL UNIVERSITY OF VIENNA</b> |
| <b>Workplace</b>   | Department of Paediatrics and Adolescent Medicine, Medical University of Vienna, Austria  |   |
| <b>Current responsibilities</b>  | Associate Professor of Paediatrics at the Vienna Medical University<br>Vice-head of the Division of Paediatric Nephrology and Gastroenterology<br>Head of the Paediatric Nephrology Research Laboratory |   |
| <b>INVOLVEMENT IN CHILD HEALTH CARE</b>  |   |   |
| Paediatrician and paediatric nephrologist.<br>Senior Consultant, National Research Centre for Maternal and Child Health, Astana, KZ.<br>Director of the “ÖGK Ernst Huber Ethical Symposium”.<br>Director “PhD Programme for Organ Failure, Replacement and Transplantation” at the Medical University Vienna.  |   |   |
| <b>PARTICULAR INTERESTING DETAILS OF CURRENT AND PAST WORK AND /OR STUDIES</b>   |   |   |
| As paediatric nephrologist at the Medical University of Vienna I am often confronted with cross-border health issues, and thereby also recognised common limitations and problems. I am further involved in cross-border activities in the field of paediatric nephrology in Astana.   |   |   |
| <b>WHAT MAKES ME KEEN ON PARTICIPATING IN THIS CONFERENCE?</b>   |   |   |
| I see this conference as a first step towards a better care for children from all over Europe. This conference might help to create networks and start task forces to further pursue the goal of reducing inequalities within Europe.  |   |   |
| <b>TWO HEALTH INEQUALITIES THAT SHOULD BE DEALT WITH URGENTLY:</b>   |   |   |
| 1  | Inequalities in education and training (need for twinning programmes).  |   |
| 2  | After-treatment of children in their home country after transplantation in Austria or any other country.  |   |
| <b>ASPECTS WHERE I OR MY ORGANIZATION COULD MAKE A USEFUL CONTRIBUTION TO ONE OR MORE ASPECTS OF CHILD HEALTH INEQUALITIES?</b>  |   |   |
| As one of the initiators of this conference, it is not my intention to only raise awareness for current inequalities. In addition to that we would like to help to link already existing projects and groups to support both local high-end care for children with major organ disease and their access to cross-border health-care. Besides, we will try to foster task forces for future European interdisciplinary network projects and specific twinning projects in paediatric renal replacement therapy (including transplantation). |   |   |



**PARTNER**



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## **ACKNOWLEDGEMENTS**

We are especially grateful for the help of Marieke Hodel and Astrid Scherr, who supported us in the organisation of this conference.

Furthermore we would like to thank Ms. Susanne Friedl and Beata Perisanidis from the Office for European Affairs and Evelin Simek from the Medical Media Services of the Medical University of Vienna.



## SPONSORS (as per Nov 15, 2011)

We would like to thank our corporate sponsors:





# NOTES





# NOTES



# NOTES



# NOTES



Please visit our homepage  
[www.bridgesforchild.eu](http://www.bridgesforchild.eu)

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