

## CURRICULUM VITAE



### PERSONAL DATA

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Name Jürg Barben  
Date of birth 31<sup>st</sup> December 1960, Aarau, Switzerland  
Address Head, Paediatric Pulmonology, Allergology & CF Centre  
Children's Hospital of Eastern Switzerland, CH-9006 St. Gallen, Switzerland  
Tel. +41 71 243 71 11, Email: [juerg.barben@kispisg.ch](mailto:juerg.barben@kispisg.ch)

### EDUCATION/TRAINING

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1980-81 Study of photography at the School of Art "Farb & Form" in Zurich  
1981-82 Study in History & Psychology at the University of Zurich  
1982-88 Study of Medicine & Thesis (MD) at the University of Zurich  
1995 Graduation (FMH) as a specialist in General Medicine  
1997 Graduation (FMH) as a specialist in Paediatrics & Adolescent Medicine  
2000 Graduation (FMH) as a specialist in Paediatric Pulmonology  
2009 Associate Professor at the Medical Faculty of the University of Basel  
2016 Elected Professor at the Medical Faculty of the University of Basel

### PROFESSIONAL ACTIVITIES

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1989 - 1996 Resident and registrar in Internal Medicine, Surgery, Neonatology and Paediatrics in different hospitals all over Switzerland  
1997 - 1998 Consultant in Paediatrics, Cantonal Hospital Münsterlingen, Switzerland  
1998 - 2000 Clinical Research Fellow, Department of Respiratory Medicine at the Royal Children's Hospital, Melbourne, Australia  
Since 2000 Head Paediatric Pulmonology, Allergology & CF centre at the Children's Hospital of Eastern Switzerland, St. Gallen

### MEMBERSHIPS

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Swiss Medical Association (FMH), Swiss Society of Paediatrics (SGP), Swiss Society for Paediatric Pulmonology (SGPP), German speaking Society for Paediatric Pulmonology (GPP), Swiss Paediatric Respiratory Research Group (SPRRG), Swiss Society of Pulmonology (SGP), European Respiratory Society (ERS), Swiss Working Group for Cystic Fibrosis (SWGCF), European Cystic Fibrosis Society (ECFS)

## COLLABORATION IN SOCIETIES & EXPERT GROUPS

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2001 - 2006	Board member Swiss Paediatric Respiratory Research Group
2003 - 2014	Secretary of the Swiss Society for Paediatric Pulmonology
2003 - 2017	Board member of the St. Gallen Lung League (President from 2003-2016)
2004 - 2012	Board member of the Swiss Society of Pulmonology
2006 - 2014	President Swiss Working Group for Cystic Fibrosis
Since 2007	Head of Task Force "Newborn Screening for CF in Switzerland"
Since 2007	Member of the ECFS Diagnostic Network Working Group (DNWG)
Since 2008	Member of the ECFS Neonatal Screening Working Group (NSWG), since 2019 coordinator
2014 - 2020	Secretary (2014-17) & Chair (2017-20) CF Group of the European Respiratory Society (ERS)
2020 - 2022	Member of the ERS Paediatrics Long Range Planning Committee

## PUBLICATIONS IN THE FIELD OF CF IN THE LAST YEARS

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Cystic Fibrosis Cases Missed by Newborn Bloodspot *Int J Neonatal Screen* 2023 Nov 21;9:65 (last author).

Standards for the care of people with cystic fibrosis - A timely and accurate diagnosis. *J Cyst Fibros* 2023;22(6): 963-8 (co-author).

Raised intracranial pressure in three children with CF receiving ETI. *Am J Respir Crit Care Med* 2023 Jul 1;208(1):103 (co-author).

Risk of false newborn screening after intra-uterine exposure to ETI. *J Cyst Fibros* 2023, July 24 (last author).

Newborn screening for CF – The good, the bad and the ugly. Editorial. *J Cyst Fibros* 2023 Jan 23

European survey of newborn bloodspot screening for CF: opportunity to address challenges and improve performance. *J Cyst Fibros* 2022 Nov (last author).

Immunoreactive trypsinogen in healthy newborns and infants with cystic fibrosis. *Arch Dis Child Fetal Neonatal Ed* 2022 Sep 8 (last author).

Standards of care for *CFTR* variant-specific therapy (including modulators) for people with cystic fibrosis. *J Cyst Fibros* 2022 Oct 27 (co-author).

Standards of care guidance for sweat testing; phase two of the ECFS quality improvement programme. *J Cyst Fibros* 2022;21:434-441 (co-author).

International Approaches to Management of *CFTR*-Related Metabolic Syndrome/Cystic Fibrosis Screen Positive, Inconclusive Diagnosis. *Int J Neonatal Screen* 2022 Jan 11;8(1):5 (co-author).

Defining key outcomes to evaluate performance of newborn screening programmes for cystic fibrosis. *J Cyst Fibros* 2021;20:820–23 (last author).

Updated guidance on the management of children with CRMS/CFSPID. *J Cyst Fibros*. 2021;20:810-819.

First description of cystic fibrosis. *J Cyst Fibros*. 2021;20:183.

Why Do We Screen Newborn Infants for Cystic Fibrosis? *Int J Neonatal Screen* 2020 Jul 8;6(3):56.

Processing Newborn Bloodspot Screening Results for CF. *Int J Neonatal Screen*. 2020 Mar 25;6(2):25

Inconclusive diagnosis after a positive newborn bloodspot screening result for cystic fibrosis; clarification of the harmonised international definition. *J Cyst Fibros*. 2019 Nov;18(6):778-780 (co-author).

International approaches for delivery of positive newborn bloodspot screening results for CF. *J Cyst Fibros*. 2019;18:614-21 (co-author).

Comparison of two sweat test systems for the diagnosis of CF in newborns. *Pediatr Pulmonol* 2019;54:264-27

ECFS best practice guidelines: the 2018 revision. *J Cyst Fibros*. 2018 Mar;17(2):153-78 (co-author).

Real life practice of sweat testing in Europe. *J Cyst Fibros*. 2018;17:325-332 (co-author).

The expansion and performance of national newborn screening programmes for CF in Europe. *J Cyst Fibros* 2017;16:207-13.

Cystic fibrosis screen positive, inconclusive diagnosis. *Curr Opin Pulm Med* 2016, 22:617–622.

Measurement of fecal elastase improves performance of newborn screening for cystic fibrosis. *J Cyst Fibros* 2016;15:313-17.

Newborn screening for cystic fibrosis – the parent perspective. *J Cyst Fibros* 2016;15:442-51 (last author).