## ISTITUTO G. GASLINI U.O.S.D. - Centro fibrosi cistica Responsabile.: Dr. Carlo Castellani



Genoa, March 1st 2024

To the European Cystic Fibrosis Society Board

I write this letter to endorse and support the application of Professor Jurg Barben for an ECFS Board position.

Professor Barben is well integrated and highly respected in the international CF research community. He is full of ideas and constantly looking for challenging questions to be addressed. He is a recognized authority in the world regarding CF neonatal screening, and in his role of Director of a Pediatric CF Center has full competence in CF care issues.

Having been the founder of the ECFS Newborn Screening Working Group, I think I can say that in his actual role of Coordinator of the Group Professor Barben has been working tirelessly, proving to be well organized and well integrated into the team. Under his leadership the WG has accomplished several projects and publications that have contributed to improve the newborn screening performance.

In brief, over the years I have learned to appreciate Professor Barben capacity for scientific research and team building, and I really believe that he has all the skills and energy needed to successfully contribute to the ECFS Board activities.

I am happy to provide further information at your request.

Sincerely

Carlo Castellani, M, Director Cystic Fibrosis Center, Gaslini Children Hospital Genoa, Italy carlocastellani@gaslini.org

# Imperial College

Professor Jane Davies Professor of Paediatric Respirology & Experimental Medicine Faculty of Medicine , Department of CF & Chronic Lung Infection National Heart & Lung Institute Imperial College London Room G44, Emmanuel Kaye Building Royal Brompton Campus Imperial College London London, UK SW3 6LR Tel: +44 (0)20 7594 7973 j.c.davies@imperial.ac.uk

27<sup>th</sup> February 2024

Dear ECFS members,

### Re: nomination of Juerg Barben for Board election

I was delighted to hear that Juerg Barben wished to stand for the Board- he is, in my opinion, exactly the sort of person we need and I urge you to consider his application. Prof Barben is an international name in CF, most notably contributing to newborn screening, which has transformed early care and outcomes for infants today. He has been a great supporter of our Society, leading the ECFS Newborn Screening Working Group and participating actively in the Diagnostic Network WG. He has authored a large number of highly-cited papers including in the latest Standards of Care series. In addition to his breadth of knowledge in CF, he has personal attributes which he would bring to the Board: he is thoughtful in his opinion and respectful of others, but unafraid to speak up if he disagrees.

As I begin my term as President, I am fortunate to have the support of a really excellent Board on which Juerg would be a further asset.

Yours sincerely,

Professor Jane C Davies Professor of Paediatric Respirology & Experimental Medicine National Heart & Lung Institute, Imperial College London Honorary Consultant in Paediatric Respiratory Medicine Royal Brompton Hospital, part of Guy's and St Thomas' NHS Foundation Trust





LEUVEN February 23rd, 2024

Subject : nominating prof Juerg Barben for ECFS board member.

Dear ECFS members,

Prof Juerg Barben is the head of the Pediatric Pulmonology department in St Gallen, Switzerland.

During my time as head of the ECFS-CTN and later on as president of the ECFS, I have had the privilege of really getting to know many of our members. As such, I have known Juerg Barben since at least 2 decades. Juerg has devoted his career to CF and his specific interest and knowledge lie in the field of CF newborn screening and CF diagnostics.

Over the years, Juerg has been increasingly involved in our European CF Society and at present he successfully leads the ECFS Neonatal Screening Working Group (NSWG).

I am very convinced that we need diversity in our ECFS board. Therefore electing a candidate from Switzerland would be a great opportunity. But more importantly, Juerg is an original thinker with a wise judgement and a team player, both of which characteristics will certainly contribute to the optimal functioning of the ECFS board. Therefore I strongly support his nomination for ECFS board member.

Kind regards

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Kris De Boeck em Prof Pediatrics University of Leuven, Belgium

#### Hadassah Medical Organization Hadassah University Hospitals



הסתדרות מדיצינית הדסה בתי החולים האוניברסיטאיים של הדסה

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אגף הילדים

March 14, 2024

Dear Christine,

We are delighted to have the opportunity to recommend Professor Jürg Barben as a candidate for election to the ECFS Board.

Prof. Jürg Barben holds the esteemed position of head of the regional pediatric CF center of Eastern Switzerland in St. Gallen, where he has made significant contributions to patient care and clinical research. His dedication to the field of cystic fibrosis is evident in his active involvement in ECFS activities, notably within the Diagnostic Network (DNWG) since 2007 and the Neonatal Screening Working Group (NSWG) since 2008. Notably, he has served as the coordinator of the NSWG since 2019, showcasing his leadership abilities and commitment to advancing the understanding and treatment of CF.

Prof. Barben's research interests are diverse and impactful, covering areas such as neonatal screening, CFSPID, and sweat testing. His expertise in these areas has contributed immensely to the development of best practices and innovative approaches within the CF community.

We have had the privilege of witnessing Prof. Barben's dedication, professionalism, and collaborative spirit firsthand, and we are confident that he will bring these qualities to the ECFS Board. His strategic vision, deep understanding of the challenges facing CF patients, and commitment to improving outcomes make him an excellent candidate for this important role.

We wholeheartedly endorse Prof. Jürg Barben's candidacy for the ECFS Board and urge you to consider him as a valuable addition to the Board.

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Thank you for considering this recommendation.

Yours sincerely,

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Prof. Michael Wilschanski

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Prof Eitan Kerem



**Co-president (children)** Pr Dr Alex Möller Universitätskinderklinik, Zürich Tel: 044 266 71 11 - alexander.moeller@kispi.uzh.ch

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**Research Commission** 

Pr Dr Philipp Latzin Kinderklinik, Inselspital, Bern Tel : 061 704 12 12 - philipp.latzin@insel.ch

Website Dr Andreas Jung Universitätskinderklinik, Zürich Tel: 044 266 71 11 - andreas.jung@kispi.uzh.ch

Zurich, 12. March 2024

Dear ECFS members,

## Re: Nomination of Jürg Barben for ECFS Board member

It is a great pleasure for me to support Professor Jürg Barben for a seat on the ECFS Board.

We have been working together for over 20 years in the care of children with CF in Switzerland. Prof. Jürg Barben has been a dedicated head of CF Centre at the Children's Hospital of Eastern Switzerland for more than two decades and is himself very active in clinical research and has conducted many studies in the field of sweat testing and newborn screening for CF.

From 2006-2014 he was President of the Swiss Working Group for Cystic Fibrosis and thanks to his tireless commitment, CF newborn screening was successfully introduced in Switzerland in 2011 and has been continuously improved thanks to extensive und scientific evaluation under his leadership.

In his role as Secretary (2014-2017) and Chair (2017-2020) of the CF Group of the European Respiratory Society (ERS), he further pushed forward the collaboration with the ECFS, the teaching of adult colleagues, and organized many meetings and symposiums.

I am very convinced that Jürg Barben would be a good team player and a great asset to the ECFS Board. Therefore, I strongly support his nomination for ECFS board member.

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Prof. Alexander Moeller Head Paediatric Pulmonology at the University Children's Hospital Zürich Co-Chair Swiss Working Group for Cystic Fibrosis (SWGCF) Chair Paediatric Assembly European Respiratory Society (ERS)

Anne Munck, MD

Referent physician for CF neonatal screening in France

Hopital Necker-Enfants Malades, CF centre Paris France

Paris, March 20<sup>th</sup> 2024

Christine Dubois Executive Director European Cystic Fibrosis Society

**Dear Christine** 

I wish to support Professor Juerg Barben's application for the upcoming ECFS Board election.

Juerg Barben is gathering the qualities required for such a responsibility.

His commitment to CF is very important with a long-standing experience in CF clinical care at pediatric ages.

He is heading the ECFS NNS working group since 2019 with evident ability to work internationally and make the meetings great and convivial. He produced important papers on the expansion of NNS programs and quality improvement.

He is acknowledged by researchers and clinicians in the European CF Society as an expert in CF field with many publications. He is part of many consensus documents, conferences, registry, etc.

Moreover, he has a lead role in the European Respiratory Society for CF, organizing many important conferences and educational trainings for younger generations over Europe and more widely.

Being at the ECFS Board will be a strength for the ECFS.

Yours sincerely,

Anne Munck

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Gießen, 03. Mar 2024

Dear Christine,

I would like to nominate Jürg Barben from Switzerland as a member of the ECFS Board. Jürg Barben is a well-known pediatric pulmonologist leading the CF-center in St. Gallen/Switzerland. As active member of the ECFS-DNWG and as coordinator of the Newborn Screening group he is internationally engaged. His commitment and contribution to the international collobaration are highly appreciated. His independency and critical discussions are well-known characteristics of Jürg Barben. The ECFS-Board and the community will benefit from his election and active contribution.

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Prof. Lutz Nährlich



#### Kevin W Southern Professor of Child Health MBChB PhD MRCP MRCPCH

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27th February 2024

Christine Dubois Executive Director European Cystic Fibrosis Society Kastanieparken 7 DK-7470 Karup Denmark

Dear Christine,

I am delighted to support Professor Jürg Barben's application to sit on the ECFS Board.

I have worked with Jürg for over twenty years and I am confident he would be an excellent Board member. He has contributed significantly to the field of CF.

Importantly he continues to be a busy clinician, leading the CF team that supports the care of families across the Eastern Region of Switzerland. He has insight into the issues that people with CF and their families face on a day-to-day basis.

His clinical research has improved the lives of people with CF through improvements in newborn screening and diagnostics.

With his lead role in the European Respiratory Society, he was able to improve the profile of CF and organise many important meetings and conferences. He is committed to education and training our next generation of CF healthcare professionals.

In 2019, Professor Barben took over as Leader of the ECFS Neonatal Screening Working Group. Subsequently that group has gone from strength to strength, producing important papers to improve screening across the globe.

He has a global view and works actively to improve CF care and access to therapies in developing services. He has no conflicts with regard to the pharmaceutical industry and this independent position will be of great benefit to the Board, should he be appointed.

Yours sincerely,

Kevin W Southern Professor of Child Health Director of the ECFS Standards of Care Committee