# Statement on Exercise Testing in Cystic Fibrosis

- Online supplement –

Helge Hebestreit1, Hubertus G.M. Arets2,3, Paul Aurora4, Steve Boas5, Frank Cerny6, Erik H.J. Hulzebos3, Chantal Karila7,, Larry C. Lands8, John D. Lowman9, Anne Swisher10, Don S. Urquhart11, for the Cystic Fibrosis Exercise Working Group

1 University Children´s Hospital, Würzburg, Germany

2 Department of Pediatric Pulmonology, Wilhelmina Children’s Hospital, University Medical Center Utrecht, Utrecht, The Netherlands

3 Child Development & Exercise Center, Wilhelmina Children’s Hospital, University Medical Center Utrecht, Utrecht, The Netherlands

4 Paediatric Respiratory Medicine and Lung Transplantation, Great Ormond Street Hospital for Children, and Portex Respiratory Unit, UCL Institute of Child Health, London, UK

5 Northwestern University Feinberg School of Medicine, Chicago/IL, USA.

6 Women's and Children's Hospital of Buffalo and University at Buffalo, Buffalo, NY

7 Service de Pneumologie et Allergologie pédiatriques, Centre de Ressources et Compétences dans la Mucoviscidose, Hôpital Necker Enfants Malades, Université Paris V – Descartes, Paris, France

7 Montreal Children's Hospital-McGill University Health Centre, Montreal, Quebec, Canada

9 Department of Physical Therapy, University of Alabama at Birmingham, Birmingham, Ala., USA

10 Division of Physical Therapy, West Virginia University, Morgantown/WV, USA

11 Department of Paediatric Respiratory and Sleep Medicine, Royal Hospital for Sick Children, Edinburgh, UK.

# Cystic Fibrosis Exercise Working Group:

|  |  |  |
| --- | --- | --- |
| Name | Background / Degree  | Position / Affiliation |
| Alarie, Nancy | BSc. P.T | Physiotherapist,Montreal Children´s Hospital, Cystic Fibrosis Clinic, Montreal, Canada |
| Alison, Jennifer | PhD, MSc, Dip Phty | Professor Respiratory Physiotherapy, The University of Sydney; Clinical Specialist Pulmonary Rehabilitation, Royal Prince Alfred Hospital, Sydney, Australia |
| Arets, Hubertus G. M.  | MD, PhD | Department of Pediatric Pulmonology,Wilhelmina Children’s Hospital,University Medical Center Utrecht,Utrecht, The Netherlands |
| Aurora, Paul | MRCP, PhD | Consultant in Paediatric Respiratory Medicine and Lung Transplantation,Great Ormond Street Hospital for Children,Honorary Senior LecturerUCL Institute of Child Health, London, UK |
| Boas, Steve R. | MD | Medical Director, The Cystic Fibrosis Center of Chicago, Associate Professor of Pediatrics, Northwestern University Feinberg School of MedicineChicago, Illinois, USA |
| Bradley, Judy | PhD, MCSP | Reader in Physiotherapy Health and Rehabilitation Sciences Research Centre Institute of Nursing and Health Research, University of Ulster, Northern Ireland. UK |
| Button, Brenda | PhD | Clinical Associate ProfessorDept. of AIRmedThe Alfred HospitalDept. Of medicine,Monash UniversityMelbourne, Victoria,Australia |
| Bye, Peter | MD, PhD | Dept Respiratory & Sleep Medicine,RPAH University of Sydney, Australia |
| Cerny, Frank | PhD | Women’s and Children’s Hospital of Buffalo, University at Buffalo, Buffalo, NY, USA |
| Cooper, Dan | MD, PhD | Professor, Institute for Clinical and Translational Science, University of California, Irvine, CA, USA |
| Duckers, Jamie | MBChb, MD | CF Consultant Physician, All Wales Adult CF Centre, University Hospital, Llandough, UK |
| Dwyer, Tiffany | PhD | Sydney Medical School, University of Sydney and Department of Respiratory Medicine,11 West, Royal Prince Alfred HospitalMissenden Road, Camperdown 2050, Australia |
| Gruber, Wolfgang  | Dr. sportwiss. | Sportwissenschaft, Sportberatung, Sportpädagogik, Enzianweg 23, 14532 Stahnsdorf, Germany |
| Hebestreit, Alexandra | MD | Pediatric Pulmonologist, Children´s Hospital, University Hospitals, Josef-Schneider-Str. 2, 97080 Würzburg, Germany |
| Hebestreit, Helge | MD | Professor of Pediatrics, Children´s Hospital, University Hospitals, Josef-Schneider-Str. 2, 97080 Würzburg, Germany  |
| Kerstan-Huber, Marta | MSc Clinical Research | Clinical Research Scientist; Physiotherapist (cf-physio.ch) |
| Hulzebos, Erik H. J. | PT, MSc, PhD. | Clinical Exercise Physiologist, Child Development and Exercise Center, Division of Pediatrics, University Children's Hospital and Medical Center, 3508 AB Utrecht, The Netherlands |
| Karila, Chantal  | MD | Pediatrician, Service de Pneumologie et Allergologie pédiatriques, Centre de Ressources et Compétences dans la Mucoviscidose,Hôpital Necker Enfants Malades, Université Paris V - Descartes, 149 rue de Sèvres, 75743 Paris Cedex 15, France |
| Lands. Larry C. | MD, PhD | Professor of Pediatrics, Montreal Children's Hospital-McGill University Health Centre, 2300 Tupper Street, Montreal, Quebec, H3H 1P3, Canada |
| Lannefors, Louise  | Reg Physiotherapist, PhD | Lund CF centre,Dept of Respiratory Medicine and Allergology, Lund University Hospital, SE-221 85 Lund, Sweden |
| Lessire, Fred |  | Zeepreventorium De Haan, Koninklijke baan 5, B - 8420 De Haan, Belgium |
| Lowman, John | PT, PhD, CCS | Department of Physical Therapy, Gregory Fleming James Cystic Fibrosis Research Center, and Center for Exercise Medicine; University of Alabama ata Birmingham; Birmingham, Alabama, USA |
| Luke Zeitoun, Mona | MD | University of California, San Francisco; Department of Pediatrics; Division of Pediatric Pulmonary Medicine |
| McIlwaine, Maggie | PT, MCSP, CPA | Cardiorespiratory Clinical Specialist, BC Children’s hospital,, Vancouver, Canada |
| Mejia-Downs, Anne  | PT, MPH, CCS | Assistant ProfessorKrannert School of Physical TherapyUniversity of Indianapolis, USA |
| Mills-Bennett, Rebekah | MSc P.T | Physiotherapist, All Wales Adult CF Centre, University Hospital, Llandough, UK |
| Möller, Alexander | MD | Head of Department pediatric pulmonology, University Children's Hospital Zurich, Switzerland |
| Morrison, Lisa | MCSP, Grad Dip Phys, BSC. | Clinical Specialist Physiotherapist in Cystic Fibrosis, West of Scotland Adutl CF Unit, Gartnavel General Hospital, Glasgow, UK |
| Murray, Joyce | M.C.S.P.Specialist Physiotherapist in Paediatric Respiratory Medicine | Regional Cystic Fibrosis Paediatric and Adolescent Unit, Royal Belfast Hospital for Sick Children 180 Falls RoadBelfast, Northern Ireland, UK |
| Nippins, Matt | PT, DPT, CCS | Massachusetts General Hospital,55 Fruit Street, Boston, MA 02115, USA |
| Orenstein, David | MD, MA | Children’s Hospital of Pittsburgh of UPMC, Universitz of Pittsburgh, Pittsburgh, PA, USA |
| Prasad, Ammani  | MD, Grad Dip Phys, FCSP | Cystic Fibrosis Unit Manager, Cystic Fibrosis Unit, Level 8 MNH, Great Ormond Street Hospital for Children, Great Ormond Street, London WC1N 3JH, UK |
| Rand, Sarah  | MSc | CF Clinical and Research PhysiotherapistCystic Fibrosis Unit, Great Ormond Street Hospital for Children NHS Foundation Trust and Portex Unit, UCL Institute of Child Health, London, UK |
| Renner, Sabine  | MD | Medical University ViennaDepartment of Pediatrics and Adolescent Medicine Division of Pulmonology, Allergology and Endocrinology Centrum of Cystic Fibrosis Waehringerguertel 18-20 A-1090 Vienna, Austria |
| Sahlberg, Margareta | Physiotherapist, PhD  | Göteborg CF-center/children, Queen Silvia Childrens Hospital, 416 85 Göteborg, Sweden |
| Schneiderman, Jane E. | Exercise Physiologist, CSEP-CEP, PhD | Exercise Medicine Research Lab, Physiological Research Unit, Division of Physiology and Experimental Medicine, Hospital for Sick Children555 University Avenue, Toronto, ON, M5G 1X8, Canada |
| Selvadurai, Hiran  | MD, MBBS, FRACP, PhD, | Professor, The Children’s Hospital, Westmead, Sydney, Australia &   University of Sydney, Australia |
| Swisher, Anne K.,  | PT, PhD, CCS | Professor, Division of Physical TherapyWest Virginia UniversityMorgantown, WV, USA |
| Urquhart, Don | MD, MRCPCH | Consultant in Paediatric Respiratory and Sleep Medicine, Royal Hospital for Sick Children, Edinburgh, UK |

Summary of the development of the statement and the Delphi process

The work on this statement was initiated during a meeting of the Exercise Research Workgroup at the North American Cystic Fibrosis Conference in 2010. The efforts were then supported by the European Cystic Fibrosis Society who established an Exercise Working Group in 2011 to develop this statement and other documents.

As a first step, Steve Boas, Helge Hebestreit, John Lowman and Don Urquhart drafted text modules summarizing the literature on exercise testing and interpretation with a special focus on CF. This information was presented at a 4-hour consensus group meeting prior to the 34th ECFS conference in Hamburg on June 8, 2011, with 18 attendees from Europe, Australasia und North America. During that meeting, the evidence was discussed openly with respect to conclusions for the statement on exercise testing. At the end of the meeting, participants completed a Delphi questionnaire with questions on the importance of exercise testing in general, the selection of patients to be tested, the staff and equipment required for conducting an exercise test, and the appropriate test protocols and measurements. The questionnaire was also sent to other experts in the field for a total of 36 responses available. Based on the discussion during the meeting in Hamburg in June 2011 and the responses to the first Delphi questionnaire, the draft manuscript was revised, circulated via email and revised again.

A second Delphi questionnaire was sent via email to the members of the group focusing more specifically than the first Delphi questionnaire on testing protocols and measurements. Furthermore, experts were asked for their recommendations to patients based on findings during the exercise test. This questionnaire was answered by 23 respondents.

A full-day meeting was held prior to the North American CF Conference on November 2, 2011 at Irvine/California. Using the information from the Delphi questionnaires, 7 experts edited the statement on exercise testing, phrased the recommendations and their respective rationales, and worked on the indications/contraindications to exercise testing. After the meeting in Irvine, the manuscript was circulated within the entire Exercise Research Workgroup and edited several times.

On June 6, 2012 the revised document was presented to 22 members of the Exercise Research Workgroup during a 5 hour meeting prior to the 35th ECFS conference in Dublin/Ireland. The group consented on some controversial issues around contraindications of an exercise test, reasons to stop a test and measurements taken during a test. Thereafter, document was circulated three more times with fine-tuning of the wording of the recommendations. A complete version of the document was then finalized during a face-to-face meeting of 14 experts at the 2012 North American CF Conference at Orlando. FL on October 11, 2012.

Based on feed-back from the ECFS and the CFF, the document was revised and revisions were discussed at the 36th ECFS conference in Lisbon on June 12, 2013.

The final document was reviewed by the ECFS, revised based on the comments received and acknowledged by the ECFS on February 17, 2014. The document was endorsed by the ERS on September 19, 2014.

The statement will be reviewed and revised in 5 years.