NEWSLETTER 3, 2022



Dear Colleagues,

Welcome to our third newsletter of 2022.

This newsletter will focus primarily on the **45th ECFS Conference 2022** (8-11th June) **in Rotterdam** and related events.

It's Conference Time! Exciting Symposia, workshops and case studies not to be missed!

1. **Pre-conference physiotherapy Short Course**: The upper airway: Practical assessment and therapy - From research to daily work practice.

Once again, we warmly invite you to participate in this inspiring course. Anyone who attended the Pro/Con debate last year, regarding the upper airway, will not want to miss this workshop for the practical and theoretical follow up, guided by an expert team of physiotherapists from France. Course numbers are limited and filling up, be sure to book your place whilst there is some availability.

You can look forward to these topics in a packed program:

- Sinus anatomy/physiology,
- CF sinus disease,
- Medical management of CF sinonasal disease,
- Nebulised drug delivery to the sinonasal region,
- Nasal instillation,
- Measurement of sinonasal disease severity,
- Surgical management of CF sinonasal disease,
- Therapeutic ultrasound,
- Retronasal drug delivery,
- Hygiene, precautions, contraindications, ... to name but a few

The pre-conference course also includes the assessment and interpretation of literature regarding **upper airways.** The course will help build on existing knowledge as well as how research results can be translated into daily working practice recommendations.

The course runs from Tuesday 7th June (8AM - 5PM) to Wednesday 8 June (8AM - 12 AM). If you have any additional questions regarding the course, do not hesitate to contact me.

2. Annual general meeting (AGM)

"International Physiotherapy Group-CF AGM" will take place on Wednesday 08 June from 13:30 to 14:30. It is accessible to all physiotherapist, who are interested.

Agenda:

- Welcome and Introduction of the Committee and Contact Persons, apologies for absence
- Chairperson report



- Secretary report
- Treasurer report
- Business arising from reports
- Miscellaneous
- Date of next meeting

We ask all country contact persons participating in the conference to attend the AGM. If country contact person is unable to attend and is handing over the voting right to the colleague, it is necessary to fill the "proxy form", which you will find in the attachment.

3. Case presentations

"IPG/CF and Physiotherapy SIG Case presentations" will take place on Wednesday 08 June from 14.30-17.00. It is accessible to all physiotherapist, who are interested.

4. **Conference** and its physiotherapy related highlights.

Physiotherapy		
Symposium Dock 10B		
Thursday, June 9, 08:30 - 10:00		
505		1
Symposium 5 - A whole new world - Physiotherapy management in good responders to modulator therapy: ideas please!		
At the end of the session, the participant will be able to:		
 Adapt to physiotherapy management and their consequences in treating patients who are good responders to modulator therapy. Increase knowledge in mucoactive agents use in good responders to modulator therapy. Identify what are the changes in physiotherapy management during pregnancy in the good responders to modulator therapy. Continue or store the physiotherapeutic consequences in the different situations? Discuss the barriers to physiotherapy treatment in the era of CFTR modulators and formulate goals. 	op modulator therapy? Wh	at
Marlies Wagner (Austria, Graz) Iana Plešková (Czech Republic, Prague)		
CF Physiotherapy Management: A time for change? Wytze Doeleman, (Netherlands, Utrecht)	08:30 - 08:52 22 min	*
Mucoactive agents: to take or not to take, that is the question. Pamela McCormack, (United Kingdom, Liverpool)	08:52 – 09:14 22 min	1
Pregnancy – what are the ch-ch-changes (chances, choices, challenges) Mathilde Legueult, (France, Nice)	09:14 - 09:36 22 min	1
Adherence; the eternal battle Klára Benešová, (Czech Republic, Prague)	09:36 – 10:00 24 min	1
All Symposium Dock 10B		
Thursday, June 9, 15:00 - 16:30		
SS01		
Special Symposium - Making time for exercise and physical activity		
At the end of the session, the participant will be able to: Describe benefits of exercise and physical activity further to latest data from ACTIVATE-CF study and the updated Cochrane review Evaluate exercise recommendations based on considerations of age, disease severity, patient preference, barriers to exercise Summarize the evidence that exercise may replace chest physiotherapy as airway clearance therapy (ACT) Discuss different approaches to design studies to examine whether exercise can replace ACT		
Helge Hebestreit Würzburg Marcella Burghard Utrecht		
ACTIVATE-CF and Updated Cochrane Review: New perspectives on the benefits of exercise and physical activity Thomas Radtke, Zurich	15:00 – 15 22 m	
Exercise recommendations are not 'one size, fits all' Mathieu Gruet, Toulon	15:22 – 15: 22 m	
Exercise as Airway Clearance - Perspectives of the CF community on exercise as replacement for chest physiotherapy Nicola Rowbotham, Nottingham	15:44 – 16: 22 m	
Exercise as Airway Clearance - Routes to designing studies to examine whether exercise can replace ACT Zoe Saynor, Portsmouth	16:06 – 16: 24 m	



Physiotherapy Workshop	
Dock 10B	
Thursday, June 9, 17:00 - 18:30	
WS10 WS10: Physical health outcomes with or without modulator therapy	
Mandy Bryon	
Thomas Radtke Zurich	
WS10.01 Impact of triple CFTR modulator therapy on airway clearance and nebuliser adherence in adults with cystic fibrosis Jayne Faulkner, Oxford	17:00 – 17:15 15 min
WS10.02 People with cystic fibrosis on elexacaftor/tezacaftor/ivacaftor therapy demonstrate improved physical activity levels and cardiovascular fitness Thomas Simon FitzMaurice, Liverpool	17:15 – 17:30 15 min
WS10.03 Impact of triple CFTR modulator therapy on urinary incontinence symptoms in adults with cystic fibrosis Jayne Faulkner, Oxford	17:30 – 17:45 15 min
WS10.04 Exploring the effects of Kaftrio on the physiotherapists' role and service provision for people with cystic fibrosis: a UK and Republic of Ireland (ROI) survey. Orla Aisling O'Beirne, Nottingham	17:45 - 18:00 15 min
WS10.05 Physical fitness and habitual physical activity in adults with cystic fibrosis - do they improve with elexacaftor/tezacaftor/ivacaftor therapy? Wolfgang Gruber, Essen	18:00 – 18:15 15 min
WS10.06 Adherence to nebulised medication in paediatric patients with cystic fibrosis following introduction of modulator therapy Mostin Hu, Cambridge	18:15 – 18:30 15 min

Physiotherapy Workshop Rotterdam A2 Friday, June 10, 15:00 - 16:30 WS14 WS14: Measuring outcomes: where physiotherapy makes a difference Emma Raywood London Wolfgang Gruber Essen	
WS14.01 Outcome measures for airway clearance – better the devil you know? Perspectives from adults with cystic fibrosis (CF)	15:00 – 15:15
Gemma E Stanford, London	15 min
WS14.02 Time to first pulmonary exacerbation (PE) in children and adolescents with cystic fibrosis (CF): insights from spirometry, Lung Clearance Index (LCI) and symptoms-limited exercise test (SLET) Alessandra Mariani, Milano	15:15 – 15:30 15 min
WS14.03 Cystic Fibrosis-Related Diabetes is not associated with maximal aerobic exercise capacity in cystic fibrosis: a cross-sectional analysis of an international multicentre trial (ACTIVATE-CF) Thomas Radtke, Zurich	15:30 – 15:45 15 min
WS14.04 The heart of the matter: is cardiac output a limiting factor for maximal exercise capacity in people with cystic fibrosis?	15:45 – 16:00
Marcella Burghard, Utrecht	15 min
WS14.05 Normal fitness data in cystic fibrosis - a scoping review	16:00 – 16:15
Owen William Tomlinson, Exeter	15 min
WS14.06 A retrospective, longitudinal analysis of pulmonary function and peak oxygen uptake in children and adults with cystic fibrosis	16:15 - 16:30
Hannah Morgan, Exeter	15 min

4. Annual report reminder

Dear contact persons, as every year, we want to ask you to send us a short annual report from your country. A report should be short summary of information regarding the number of CF physiotherapists (perhaps with the number of CF patients they manage), recent activities and planned events in the country.

- your reports will be available to other physiotherapists in the next issue of the IPG / CF newsletter
- Deadline of submitting the **annual report is prolonged till 25th May,** on email: jana.pleskova@fnmotol.cz

If you are receiving this newsletter, we are happy for you to forward it to your CF interested colleagues.

As always, we welcome your feedback and input. Enjoy!

Jana Plešková, MSc (<u>jana.pleskova@fnmotol.cz</u>) IPG/CF Secretary

Gipg/cf contact list for member countries

Below is the contact list as of February 2021. In summary, there are currently 41 member countries receiving our correspondence.

Country	Contact	Email
Argentina:	Patricia Ratto	patricianancyratto@gmail.com
Australia:	Brenda M. Button	b.button@alfred.org.au
Austria:	Marlies Wagner	marlies.wagner@medunigraz.at
Bangladesh:	Md.Abdullah Al-Mamun	abdullah15ca@yahoo.ca
Belgium:	Myriam Vreys	myriam.vreys@uzleuven.be
Brazil:	Marcio Donadio	mdonadio@pucrs.br
Canada:	Nancy Alarie	nancy.alarie@muhc.mcgill.ca
Costa Rica:	Rodolfo A. Bonilla Abarca	rhbonilla@yahoo.com
Croatia:	Anja Kladar	anja.kladar@gmail.com
Czech Republic:	Jana Pleskova	jana.pleskova@fnmotol.cz
Denmark:	Lue Philipsen	luephilipsen@hotmail.com
Ecuador:	Maite Mijares	maite@crespomijares.com
El Salvador:	María Azucena Flores Alemán	mafa.azucena@gmail.com
Finland:	Katrr Partanen	katri.partanen@suomenfysiotera- peutit.fi
France:	Hugues Gauchez	hgauchez@hotmail.fr
Germany:	Jovita Zerlik	jovita.zerlik@kinderkrankenhaus.net
Greece:	Kostas Katsoulakis	katsoul@freemail.gr
Hong Kong:	LAU Mo Yee, Polly	alumni@polyu.edu.hk
India:	Sumita Gupta	bisoiak@rediffmail.com
Ireland:	Sarah Kelly	sarah.kelly@svuh.ie, Sodkelly@ya- hoo.ie

Israel:	Eynav Manor	e_manor@rambam.health.gov.il
Italy:	Luigi Graziano	luigi.graziano@uniroma1.it
Macedonia:	Blazhe Arsov	president@mfz.mk
New Zealand:	Roisin Varley (new)	RoisinV@adhb.govt.nz
Norway:	Sandra Gursli	sangur@ous-hf.no
Oman:	Kamla Al-Qasmi	kaq83@yahoo.com
Palestine:	Amal Nassar	amal.nassar@crb-mail.org
Poland:	Natalia Jeneralska	natalia.jeneralska@gmail.com
Portugal:	Ana Filipa Rocha	anafilipa777@hotmail.com
Romania:	Bogdan Almaja-Guta	bogdisport@yahoo.com
Serbia:	Valentina Pavković	malavanja78@gmail.com
Slovakia:	Petra Kolcúnová	kolcunova11@gmail.com
Spain:	Laura Muelos Gomez	lauramgfisio@hotmail.com
Sweden:	Cecilia Rodriguez Hortal	Cecilia.rodriguez-hortal@region- stockholm.se
Switzerland:	Bozana Agustoni	bozana.agustoni@gmail.com
The Nether- lands:	Sandra Jongenotter- Vermeulen	s.m.vermeulen@erasmusmc.nl
Turkey:	Osman Coban	oscoban28@gmail.com
UAE:	Saeid Rahbar Soureh	saeid849@yahoo.com
UK:	Hannah Langman	hannah.langman@mft.nhs.uk
Uruguay:	Kitty Löwensberg	kittylowensberg@movinet.com.uy
USA:	Jaime Eilbacher	EILBACHER@email.chop.edu

Gipg/cf contact list for alumni members

Name	Email
Esta Tannenbaum	esta.tannenbaum@rch.org.au
Helen Parrott	H.Parrott@rbht.nhs.uk
Irene Maguire	babasmurf@hotmail.com
Louise Lannefors	llannefors@gmail.com
Maggie McIlwaine	mmcilwaine@cysticfibrosis.ca
Margareta Sahlberg	margareta.sahlberg@telia.com
Ruth Dentice	Ruth.dentice@sswahs.nsw.gov.au
Cecilia Rodriguez Hortal	Cecilia.rodriguez-hortal@sll.se
Marta Kerstan	mkerstan@hispeed.ch

Alumni member

Past country contacts or board members who wish to join our Alumni members should contact our Secretary Jana with details of their terms with the IPG/CF and their areas of expertise/interest. We are compiling a list of experienced alumni members who might help us with conference preparations, and they will receive all IPG/CF communications directly as supporters of the IPG/CF.