Dear all, welcome to our second Newsletter for 2018!

I am excited we will meet soon in person in Belgrade for the ECFS and our AGM! A few things first:

Notice of our AGM for 2018 is included in this newsletter with a proxy form if your country contact person is unable to be present. These can be scanned and emailed to me or handed to me on arrival to the AGM when signing in. There is also a call for nominations for a new treasurer to commence at the 2018 AGM. The minutes of our AGM in 2017 (Sevilla) are also included in this newsletter.

Because of the fact that Cecilia is on maternity leave, Marta stepped in the role of the Chair-person of the IPG/CF – a great thank you to Marta. To think about the near future – the board members discussed to change the roles of Marta and Ceci – so that Marta can take over the chair in the period from 2018-2019 officially. This has to be confirmed in the next AGM at Belgrade.

Enclosed please find a copy of the Agenda for the meeting.

Updated reports are now due from all country contacts to be submitted at our June AGM at the ECFC. Annual reports do not need to be lengthy, they just need to provide information regarding the number of CF physiotherapists (perhaps with the number of CF patients they manage), recent activities and planned events.

If you are receiving this newsletter we are happy for you to forward it to your colleagues. As always we welcome your feedback and input. Enjoy!

Marlies Wagner, MSc (<u>marlies.wagner@medunigraz.at</u>) IPG/CF Secretary

## ECFC in Belgrade

What an exciting programme of events awaits us at Belgrade this year! The IPG has been busy putting together the content for the ECFC in Belgrade and it looks like a very stimulating conference this year. Please visit the ECFC website where you can now access the programme <a href="https://www.ecfs.eu/scientific-programme">https://www.ecfs.eu/scientific-programme</a>

I would however like to take this opportunity to draw your attention to the sessions with physiotherapy- related content (see below). Thank you to all of the speakers presenting on the pre conference course, there should be plenty of opportunity of discussion with a friendly debate to liven the audience and case studies throughout the 1.5 days. I hope that many of you will be able to attend.

We particularly hope to see you at our AGM, the case presentation session and our symposium, which is moderated by Marta Kerstan and Ruth Dentice - not to be missed!

The pre conference course topic is "AIRWAY CLEARANCE TECHNIQUES: BASIC APPROACH" and we look forward to seeing many of you in the audience. We have a fantastic line up of speakers and moderators and we hope some thoughtful discussion and learning will be generated. If you wish to secure a final place, please register on the ECFC website via the online registration platform <a href="https://www.ecfs.eu/belgrade2018/registration/registration-information">https://www.ecfs.eu/belgrade2018/registration/registration-information</a>

## Treasurer elect

At the AGM in June, we need to elect the treasurer for another three-year period. This person **DOES NOT** need to be a current or past country contact person in order to be eligible according to our constitution Thus, if you would like to join a fun and welcoming IPG board please do consider this post. You will be responsible for the IPG/CF finances, collecting subscriptions and keeping its books of account however, there is plenty more to do! You will be involved in the planning of the ECFC pre conference courses and can contribute to the sub-committees of the IPG and the ECFC content planning. We are now calling for nominations. Please complete the form below and send it back to me at marlies.wagner@medunigraz.at by 1st June 2018, or hand to me in person at the AGM when signing in.

We already got a first nomination – Peter Suter is our first announced candidate – he is willing to do this job another three-year period!

# INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

June 2018- June 2021 (Three years)

**Treasurer** 

## **Nomination Form**

For the period:

Date:

For IPG/CF position (office):

	1	• ,
Name	of cand	idate:
Reaso	ns for re	ecommendation:
Nami		y (maaamman dad lay).
Nomii	-	(recommended by):
	1. 2.	
	itution s	
K	Secret	ary/Treasurer
	(a) Person	Any two Contact Persons or two ordinary members of the Committee or one Contact and one ordinary member of the Committee may make a nomination.
	(b)	A nominee does not need to be a National Contact person. Any Physiotherapist can

be nominated. If they are not a National Contact Person, then they require one of the nominees to be their country's National Contact Person. For voting purposes, the National

Contact Person shall maintain the voting right for their country. If a Physiotherapist nominated is not the National Contact Person, the current Contact Person, from that

particular country, must not be currently on the Committee.



# Notice of the 2018 AGM of the IPG/CF

Notice is hereby given of the Annual General Meeting of the International Physiotherapy Group for Cystic Fibrosis to be held Wednesday 6<sup>th</sup> June 2018 at 12:30 in Room 4 immediately following the conclusion of our short course. If you are unable to attend, please email your Proxy vote to the secretary marlies.wagner@medunigraz.at - have your proxy bring it to the meeting.



## INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC **FIBROSIS**

## **Proxy**

I, the undersigned	
Of (State, Country)	
One of the Contact Persons (ordinary commit	tee members) of the International Physiotherapy
Group for Cystic Fibrosis (IPG/CF),	
do hereby appoint	
as my deputy delegate, or the Secretary of the	e IPG/CF, as my proxy to vote in my stead at the
Annual General Meeting of the IPG/CF to be	held on
ata	nd any adjournment thereof.
Date	
Signature	
Name in print	



## Belgrade, Wednesday, 6th June 2018, from 12.30 to 14.00

- 1) Introduction of the Committee and Contact Persons, apologies for absence.
- 2) Minutes of the Annual General Meeting held in Sevilla
- 3) Reports: Oral reports will be limited to 3 minutes; the full reports will be published in the IPG/CF Newsletter 3/2018
  - a. Chairperson
  - b. Treasurer
  - c. Secretary
  - d. Business arising from reports
- 4) Confirmation of board member change
- 5) Elect of treasurer
- 6) Elect of research representative and lead of education sub-committee (1 year terms)
- 7) Any other business and date of next meeting

# MINUTES OF THE ANNUAL GENERAL MEETING OF THE INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

## Sevilla, Wednesday, 7<sup>th</sup> June 2017, from 12:30 to 14:00

1) Introduction of the Committee and Contact Persons, apologies for absence.

Helen Parrott, IPG/CF Chairperson opened the meeting by welcoming everyone. Introduction of the board:
Cecilia Rodriguez, Vice-Chair
Marlies Wagner, Secretary
Peter Suter, Treasurer

- 1. IPG/CF contact persons were asked to stand and introduce themselves. AGM was attended by 13 CP from Australia, Austria, Belgium, Canada, Czech Republic, Denmark, France, Germany, Ireland, Norway, Portugal, Sweden, Switzerland, and UK.
- 2. IPG/CF Board received 1 proxy: Czech Republic

3. One Alumni member and 32 guests attended AGM.

Thus there were 13 contact members present and 1 proxie. This represented a quorum of current active countries and the meeting was officially opened by Chairperson of the IPG/CF.

- 2) Thank you to Cecilia Rodriguez and Ana Fillipa for organizing the physio short course
- 3) Reports:
  - 1. IPG/CF Chairpersons report 2017

## My last AGM

I have now completed my term as Chair of the IPG/CF and hand over the reins to Ceci wishing her lots of luck. I have loved been a part of this international community, responding to your emails and feedback and organising the physio content of the conference. I would like to thank the past and current board members for all of their support and helping me when I needed advice, in particular Ruth, Brenda and Irene. I wish Ceci lots of luck as chair and offer you my continued support. I am supposed to present her with the 'IPG/CF gavel' which was given to the IPG/CF by the lovely Jennifer Prior however, as it looks like a weapon, I thought it would be too risky to carry this on the plane so I will have it couriered to you!

I will also be stepping down from my role as UK country contact in January when there will be a new rep elected by the ACPCF at their AGM. I would therefore like to now join the IPG/CF alumni and will continue responsibilities with regard to editing the blue booklet and supporting the online course.

My advice to the IPG on my departure:

- Increase your project sub-groups and engage people willing to give a bit of time there is too much work for the conference for the board to complete whilst pushing forward projects and collaborating with others
- Regularly ask country contacts what the membership want from this international group the survey monkey from last year was helpful in guiding us this year
- Consider how to spread the expertise further than face-face training, how can we do things differently and reach a wider audience?

### Alumni

Can I urge country contacts that have been in their position for a while and are not interested in taking a board position in the near future to consider relinquishing the role to allow people with time to spare to come on board and move the IPG forward.

## Airway clearance instructors course

I put a call out in the last newsletter for any interest in an airway clearance instructors course and have had quite some interest. We will be considering whether we need to run this again or if indeed we could do this differently and recruit people to assist with an online training module. We will provide more information on this soon.

### **IPG** research representative

This was a suggestion from last years' survey monkey and Maggie McIlwaine was elected by country contacts at the AGM in Seville. This idea of this role is for members to be able to access research expertise to help with writing abstracts, applying for research funding or just getting an opinion on a physio research idea. There will be more information coming up in the newsletter about how to get in touch with Maggie!

Wishing you all the best for the rest of this year!

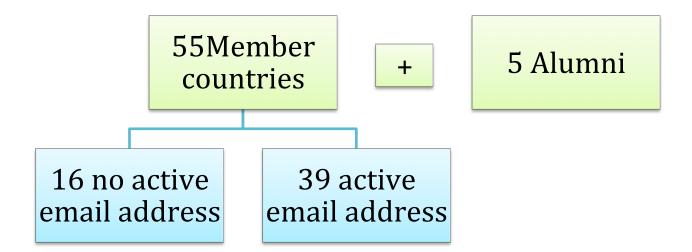
Helen Parrott Outgoing Chairperson

## 2. IPG/CF Treasurer Report – 2017

Balance IPG/CF	30.06.2016 - 05.06.2017			
Description	Date	Credit EUR	Debit EUR	Balance EUR
Balance	30.06.2016			4509.56
Bank fees	30.09.2016		15.33	
Bank fees	31.12.2016		13.96	4480.27
Annual Fee Germany	08.03.2017	50.00		
Bank fees	31.03.2017		17.19	
Annual Fee Switzerland	22.05.2017	50.00		4563.08
Total	05.06.2017	4609.56	46.48	4563.08
Annual Fee paid cash at AGM NO/AUSTR/IR/ISR	07.06.2017	200.00		4763.08

## 3. IPG/CF Secretary Report June 2017

Marlies Wagner, the IPG/CF Secretary informed in her report that IPG/CF had 39 active member countries of the 55 members.



Two newsletters had been circulated this year prior to the AGM. Annual country reports were submitted by 4 country contacts (till now): Austria, Belgium, Germany and Sweden

## 4) Elect of new Vice-Chair

Cecilia Rodriguez Hortal was welcolmed as incomming Chairperson.

Within the Chair report the call for a new vice-chairperson was anounced. One nomination (from Brenda Button and Irene Marguire) was received for the role of Vice Chair: Following a blind ballet by country contacts present, **Marta Kerstan** was unanimously elected and welcomed as IPG/CF Vice Chairperson.

## 5) Any other business and date of next meeting

## Election of IPG research representative

One nomination was received for this role. Following a blind ballet by country contacts present, Maggie McIlwaine from Canada was unanimously elected and welcomed. She should be contacted for any research question - mmcilwaine@cw.bc.ca

Date of next Meeting: ECFS conference 2018, Belgrade/Serbia (day to be confirmed) At the end of this AGM Helen expressed her sincerest thanks to all participants for active cooperation and invited them all to ECFS conference 2018 in Serbia.

# IPGCF June 2017 - June 2018 ANNUAL REPORTS FOR MEMBER COUNTRIES

## Annual report from Austria 2017-2018

There are 16 CF centers in Austria, caring for approx. 800 CF patients in in- and outpatient settings in multidisciplinary teams. In addition, there are 2 centers for rehabilitation specialized in CF. The group of CF-physiotherapists includes approx. 50 members.

There is at least an annual meeting of the group and additionally meetings of the Austrian group of cardiorespiratory physiotherapists within the framework of the Austrian Society of Pneumology. Recently, we integrated CF-physiotherapists who are not specialized in pneumology but working with CF patients (mostly from small centers), in this group, with the aim to increase nationwide quality standards in the daily treatment routine with CF patients. The group actively contributes with lectures and symposia to the annual conference of the Austrian Society of Pneumology as well as to international CF meetings. There are also several advanced training courses to teach and train colleagues, patients and their relatives.

Marlies Wagner, 2018-05-06

E-mail: marlies.wagner@medunigraz.at

## Annual report from Canada 2017-2018

We currently have approximately 50 therapists involved in CF care across Canada. Several therapists manage over 200 patients either adult or pediatric. Certain smaller centers have both pediatric and adult patients in the same clinic. Currently in Canada there are over 4200 CF patients followed in 42 CF multidisciplinary clinics across the Country. In 2016 the current median age is 22.7 years and the estimated age of survival is 53.3 years. In 2016, 60.8% of the CF population in Canada are adults. In the clinics our therapists are involved in the teaching and monitoring of airway clearance techniques to the families and to the patients. Ongoing education is an integral part of the physiotherapist's role in the clinic. They are also involved in the airway clearance management of these patients during hospital admissions. Exercise is also an integral component of CF care and many of our therapists are involved in assessing exercise and exercise prescription. We meet as a group once a year at the North American Cystic Fibrosis Conference. Our goal this year is to work toward establishing a mentoring program.

Here is the distribution of patients by province

Province	Total patients	Adult/Pediatric
Alberta	587	335/252
British Columbia	424	258/166
Manitoba	113	57/56
New-Brunswick	45	32/13
Newfoundland	74	54/20
Nova-Scotia	236	145/91
Ontario	1473	885/588
Quebec	1198	761/437
Saskatchewan	129	69/60

Nancy Alarie, 2018-04-13

E-mail: nancy.alarie@muhc.mcgill.ca

## **IPGCF CONTACT LIST FOR MEMBER COUNTRIES**

Below is the contact list as of May 2018. In summary, there are currently 39 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:	Hilda Angelica Jimenez	hildajimenez38@yahoo.com.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
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Ecuador:	Maite Mijares	maite@crespomijares.com
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Greece:	Kostas Katsoulakis	katsoul@freemail.gr
Hong Kong:	LAU Mo Yee, Polly	pmylau@ha.org.hk
India:	Sumita Gupta	bisoiak@rediffmail.com
Ireland:	Louise Collins (new)	louisee.collins@hse.ie
Israel:	Eynav Manor	e_manor@rambam.health.gov.il
Italy:	Simone Gambazza (new)	simone.gambazza@policlinico.mi.it
Macedonia:	Minola Paunovska	oliverdod@gmail.com
New Zealand:	Rebecca Scoones	RScoones@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:	Anna Filipa Rocha	AnaFilipa777@hotmail.com
Romania:	Bogdan Almaja-Guta	bogdisport@yahoo.com
Slovakia:	Marta Heroutová	fyzio.pp@falck.sk
Spain:	Laura Muelos Gomez	lauramgfisio@hotmail.com
Sweden:	Cecilia Rodriguez Hortal	Cecilia.rodriguez-hortal@sll.se
Switzerland:	Marta Kerstan	mkerstan@hispeed.ch
The Netherlands:	Lianne van der Giessen	I.vandergiessen@erasmusmc.nl
Turkey:	Osman Coban	oscoban28@gmail.com
UAE:	Saeid Rahbar Soureh	saeid849@yahoo.com

UK:	Hannah Langman	hannah.langman@mft.nhs.us
Uruguay:	Kitty Löwensberg	kittylowensberg@movinet.com.uy
USA:	Jaime Eilbacher	EILBACHER@email.chop.edu

## IPGCF CONTACT LIST FOR ALUMNI MEMBERS

Name	Email
Esta Tannenbaum	esta.tannenbaum@rch.org.au
Helen Parrott	H.Parrott@rbht.nhs.uk
Irene Maguire (new)	babasmurf@hotmail.com
Louise Lannefors (new address)	louise.lannefors@gmail.com
Maggie McIlwaine	mmcilwaine@cw.bc.ca
Margareta Sahlberg	margareta.sahlberg@telia.com
Ruth Dentice	Ruth.dentice@sswahs.nsw.gov.au

## Alumni member

Past country contacts or board members who wish to join our Alumni members should contact our Secretary Marlies 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. Thank you to Irene for joining the Alumni members!

## IPGCF TREASURERS REPORT JANUARY 2018

Dear Members of the IPG/CF, Dear Country Contact Persons,

Welcome to 2018 and all the best to each of you!

Although a lot of things may change in our lives, certain things stay the same, like my reminder to pay the annual fee for the IPG/CF.

The annual fee is not compulsory; nevertheless I invite all countries, which are able to do so, to participate.

Although, we are aware that not all member countries are financially equally strong, I would like to ask you to check in your organization whether it would be possible for your country to pay the 50 Euro Annual Fee.

What is the money needed for?

Mainly for speakers at the CF-Conference, who are not funded by the Organizing Committee, special occasions and bank fees.

The IPG/CF Board works voluntarily. No Salary or expenses are paid to them.

## The annual fee of 50 Euro is due by June 30, 2018

There are two methods for payment:

1. Payment to the IPG/CF bank account. Bank details are as follows:

Bank Name: Credit Suisse 8070 Zürich

Address: cf-physio.ch, Artishus 1, 3527 Grossaffoltern, Switzerland

IBAN: CH51 0483 5163 5631 6200 0

BIC: CRESCHZZ80A

Account Nr: 0094-1635631-62

Account Name: CFinternational

Currency: EURO! Not Swiss Francs

Please declare clearly for which **country and year** you are paying e.g. Switzerland 2018

2. Cash payment to me at the Annual General Meeting on June 6, 2018 at the ECFS Conference in Belgrade

In both cases, the currency must be in EURO and you will receive a receipt. Should another person be in charge of making the payment, please pass this information on to them.

## The balance of the IPG/CF in December 2017 was 3,515.47 Euro.

Thank you very much for your cooperation. If you need information or have a question don't hesitate to contact me.

Kind regards,
Peter Suter
IPG/CF Treasurer Peter.Suter@usb.ch

## IPG Highlights in Belgrade

## PHYSIOTHERAPY SHORT COURSE \*\* AIRWAY CLEARANCE TECHNIQUES: BASIC APPROACH

Tuesday 5 June & Wednesday 6 June - 1,5 Day

This course is intended for physiotherapists, physical or respiratory therapists who require basic training in the physiological basis, practical application of ACT therapies, including inhalation. This course will be a stimulating and interactive teaching approach to airway clearance techniques and how to go from research interpretation to daily working practice recommendations.

https://www.ecfs.eu/belgrade2018/meetings

Room 4

06.06.2018, 14:30 – 17:00

**Physiotherapy Case Presentations** 

#### **Chairs**

#### **Presentations**

Personalised airway clearance in the newborn: is it possible? Maggie McIlwaine, Vancouver, Canada

Case study of physiotherapy management of a premature baby with cystic fibrosis and Tracheal Bronchus

Niamh Kiernan, Glasgow, United Kingdom

Intelligent volume assured pressure support modes of ventilation in severe end stage cystic fibrosis

Zelda Beverley, London, United Kingdom

Case report of severe pulmonal deterioration in child with cystic fibrosis and chronic MRSA infection

Irena Cakalaroska, Skopje, Macedonia

Lung transplantation: exercise matters! Federica Carta, Milano, Italy

Symposium, Annex A 07.06.2018, 08:30 – 10:00 Evolving the role of physiotherapy

#### Chairs

Marta Kerstan, Biberstein, Switzerland Ruth Dentice, Sydney, Australia

#### **Presentations**

Arthropathy and arthritis

Elizabeth Clarke, Manchester, United Kingdom

Coaching for success, the upper airway William Poncin, Brussels, Belgium

Incontinence Sophie Ramel, Roscoff, France

How to treat pain? Dominique Hubert, Paris, France

Workshop, Hall 2 07.06.2018, 17:00 – 18:30 Exercise: the fitter the better!

#### Chairs

Helge Hebestreit, Würzburg, Germany Marta Kerstan, Biberstein, Switzerland

#### **Presentations**

The utility of oxygen uptake efficiency as a marker of aerobic fitness in children with cystic fibrosis Owen Tomlinson, Exeter, United Kingdom

Acute effects of combined exercise and oscillatory positive expiratory pressure therapy on sputum properties and lung diffusing capacity in cystic fibrosis: a randomised, controlled, crossover trial

Thomas Radtke, Zurich, Switzerland

Combined ramp and supramaximal cardiopulmonary exercise testing for individuals with cystic fibrosis

Zoe Saynor, Portsmouth, United Kingdom

Feasibility of an incremental step test to assess aerobic fitness in adult cystic fibrosis Zelda Beverley, London, United Kingdom

Balance, flexibility and agility - additional aspects of physical fitness and trainability in children and adolescents with cystic fibrosis

Wolfgang Gruber, Essen, Germany

Effects of home-based adapted physical activity in patients with cystic fibrosis: an interventional study

Boubou Camara, Grenoble, France

ePoster Session, ePoster Corner C 08.06.2018, 14:00 – 15:00 Mixing up physiotherapy

#### Chairs

Jamie Wood, Perth, Australia Peter Suter, Basel, Switzerland

#### **Presentations**

Shaking it up: a look at our center experience with high frequency chest wall oscillation (HFCWO): Carwyn Bridges, Cardiff, United Kingdom

Investigating the experience of adults with cystic fibrosis using long-term domiciliary non-invasive ventilation: Jocelyn Choyce, Birmingham, United Kingdom

Hypertonic saline use in our paediatric cystic fibrosis centre: using the UK cystic fibrosis Registry to reflect on practice: Rachel O'Connor, London, United Kingdom

Correlation between six-minutes-walk-test and cystic fibrosis disease severity Elad Ben-Meir, Ramat Gan, Israel

A-STEP: a maximal, incremental, externally paced step test for adults with cystic fibrosis - safety and feasibility testing: Lisa Wilson, Melbourne, Australia

Influence of a supervised exercise program (CF*mobil*) on motor ability in adult cystic fibrosis patients: Matthias Welsner, Essen, Germany

Effects of physical retraining on the body composition of adult patients with cystic fibrosis Anne Prevotat, Lille, France

The effects of Orkambi therapy on muscle strength, function, body composition and quality of life in cystic fibrosis patients homozygous for *CFTR*-F508del: Clare M. Reilly, Dublin, Ireland

## **Workshop,** Hall 2 08.06.2018, 15:00 – 16:30

Assessing the patient: it's not all about the chest

### **Chairs**

Andrew Jones, Manchester, United Kingdom Fiona Cathcart, London, United Kingdom

#### **Presentations**

Thoracic ultrasound as a useful tool to assess lung atelectasic areas and set the best physiotherapy
Matteo Giuliari, Rovereto, Italy

Musculoskeletal symptoms in adults with cystic fibrosis Elizabeth Clarke, Manchester, United Kingdom

The impact of pain on physiotherapy care in cystic fibrosis Anna Meschi, Verona, Italy

Experiences of non-invasive ventilation in a large adult cystic fibrosis centre and nationally Zelda Beverley, London, United Kingdom

Assessment of the prevalence and severity of urinary and ano-rectal functional disorders and their impact on quality of life and sexuality in adult with cystic fibrosis in the French North-West Cystic Fibrosis Network

Sophie Ramel, Roscoff, France

Urinary incontinence in adult patients with cystic fibrosis: prevalence, impact on daily life and relationship with chronic cough Ernesto Crisafulli, Parma, Italy

Please feel free to provide feedback and forward your suggestions or content to the IPG/CF secretary – <a href="marlies.wagner@medunigraz.at">marlies.wagner@medunigraz.at</a>
Distribute this widely, and enjoy!