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Identification

Working Group on: Myocardial and Pericardial diseases

Nucleus Composition

Chairperson: Alida LP Caforio, Italy

Vice-chairperson: Ales Linhart, Czech Republic

Past chairperson: Philippe Charron, France

Treasurer : Karin Klingel, Germany

Secretary: Angelos Rigopoulos, Germany

Nucleus Members 1-Massimo Imazio, Italy (web editor)
2-Yehuda Adler, Israel
3-Aristides Anastasakis, Greece
4-Michael Arad, Israel
5-Pablo Garcia-Pavia, Spain (representative for
Council Basic Cardiovascular Science)
6-Antonis Pantazis (education program manager)

Specific Committees:

1-Study Group on Pericardial Diseases & Interventional Pericardiology (Coordinators: M. Imazio/Y. Adler)

2- Study Group on Inherited Cardiac Diseases (Coordinators: A Anastasakis/ M. Arad)

3- Study Group on Inflammatory and infective heart muscle diseases (Coordinators: K. Klingel /A. Caforio)

Elections in 2015

-NONE

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Activities of the Working Group on Myocardial and Pericardial Diseases in 2015

Meetings

(For each meeting, please precise titles, dates, places, number of participants):

WG Annual Meeting(s):

- 11th meeting of the Myocardial and Pericardial Diseases Working group of the European Society of Cardiology, February 4-6, 2015, Dan Tel-Aviv Hotel, Tel-aviv, Israel, 180 delegates in total.
- 12th meeting of the Myocardial and Pericardial Diseases Working group of the European Society of Cardiology, III Florence International Symposium on Advances in Cardiomyopathies, October 22-24, 2015, Convitto della Calza, Florence, Italy, 438 delegates in total (366 registered participants and 72 faculty members)

Endorsed Meeting(s):

- European Symposium on rare cardiovascular diseases, Joint meeting between the Monaldi-SUN, and UCL, March 4-6, 2015 Monaldi-SUN Hospital, Naples, Italy
- International Workshop on Rare Cardiovascular Diseases and Regional congress of Crete Division of the Hellenic Cardiological Society, May 22-24, 2015, Center of Mediterranean Architecture, Chania, Crete, Greece
- Course on multimodality imaging and myocardial diseases, May 30-31, 2015, Athens, Greece

Education programme(s) – Training, Courses & Grants:

- unrestricted Educational grant: Shire, 30 K€
- unrestricted Educational grant: Genzyme, 35 K€
- Webinar: Clinical presentation, diagnosis and treatment of myocarditis, September 15, 2015. This webinar was held with more than 400 connections and now recording of the Webinar is online:

<http://www.escardio.org/Guidelines-&Education/E-learning/Webinar-recordings/Myocardial-and-pericardial-diseases/clinical-presentation-diagnosis-and-treatment-of-myocarditis>

=> Costs of this webinar was around 9.300 € (travel, accommodations, studio service and management fees)

Papers & Guidelines

Publications & Scientific Papers submitted by the WG:

- Mogensen J, van Tintelen JP, Fokstuen S, Elliott P, van Langen IM, Meder B, Richard P, Syrris P, Caforio AL, Adler Y, Anastasakis A, Gimeno JR, Klingel K, Linhart A, Imazio M, Pinto Y, Newbery R, Schmidtke J, Charron P. The current role of next-generation DNA sequencing in routine care of patients with hereditary cardiovascular conditions: a viewpoint paper of the European Society of Cardiology working group on myocardial and pericardial diseases and

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members of the European Society of Human Genetics. *Eur Heart J*. 2015 Jun 7;36(22):1367-70.

- Ristić AD, Imazio M, Adler Y, Anastasakis A, Badano LP, Brucato A, Caforio AL, Dubourg O, Elliott P, Gimeno J, Helio T, Klingel K, Linhart A, Maisch B, Mayosi B, Mogensen J, Pinto Y, Seggewiss H, Seferović PM, Tavazzi L, Tomkowski W, Charron P. Triage strategy for urgent management of cardiac tamponade: a position statement of the European Society of Cardiology Working Group on Myocardial and Pericardial Diseases. *Eur Heart J*. 2014 Sep 7;35(34):2279-84.

- Pinto YM, Elliott PM, Arbustini E, Adler Y, Anastasakis A, Bohm M, Duboc D, Gimeno J, de Groote P, Imazio M, Heymans S, Klingel K, Komajda M, Limongelli G, Linhart A, Mogensen J, Moon J, Pieper PG, Seferovic PM, Schueler S, Zamorano JL, Caforio ALP, Charron P. Proposal for a Revised Definition of Dilated Cardiomyopathy and its Implications for Clinical Practice: A Position Statement of the ESC Working Group on Myocardial and Pericardial Diseases. *Eur Heart J* 2015 (accepted, in press)

Guidelines participation (writing or reviewing)

- Authors/Task Force Members, Adler Y, Charron P, Imazio M, Badano L, Barón-Esquivias G, Bogaert J, Brucato A, Gueret P, Klingel K, Lionis C, Maisch B, Mayosi B, Pavie A, Ristić AD, Sabaté Tenas M, Seferovic P, Swedberg K, Tomkowski W; Document Reviewers, Achenbach S, Agewall S, Al-Attar N, Angel Ferrer J, Arad M, Asteggiano R, Bueno H, Caforio AL, Carerj S, Ceconi C, Evangelista A, Flachskampf F, Giannakoulas G, Gielen S, Habib G, Kolh P, Lambrinou E, Lancellotti P, Lazaros G, Linhart A, Meurin P, Nieman K, Piepoli MF, Price S, Roos-Hesselink J, Roubille F, Ruschitzka F, Sagristà Sauleda J, Sousa-Uva M, Uwe Voigt J, Luis Zamorano J. 2015 ESC Guidelines for the diagnosis and management of pericardial diseases: The Task Force for the Diagnosis and Management of Pericardial Diseases of the European Society of Cardiology (ESC) Endorsed by: The European Association for Cardio-Thoracic Surgery (EACTS). *Eur Heart J*. 2015 Nov 7;36(42):2921-64.

- Authors/Task Force Members, Priori SG, Blomström-Lundqvist C, Mazzanti A, Blom N, Borggrefe M, Camm J, Elliott PM, Fitzsimons D, Hatala R, Hindricks G, Kirchhof P, Kjeldsen K, Kuck KH, Hernandez-Madrid A, Nikolaou N, Norekvål TM, Spaulding C, Van Veldhuisen DJ. 2015 ESC Guidelines for the management of patients with ventricular arrhythmias and the prevention of sudden cardiac death: The Task Force for the Management of Patients with Ventricular Arrhythmias and the Prevention of Sudden Cardiac Death of the European Society of Cardiology (ESC) Endorsed by: Association for European Paediatric and Congenital Cardiology (AEPC). *Eur Heart J*. 2015 Aug 29. pii: ehv316.

- Authors/Task Force Members, Priori SG, Blomström-Lundqvist C, Mazzanti A, Blom N, Borggrefe M, Camm J, Elliott PM, Fitzsimons D, Hatala R, Hindricks G, Kirchhof P, Kjeldsen K, Kuck KH, Hernandez-Madrid A, Nikolaou N, Norekvål TM, Spaulding C, Van Veldhuisen DJ. 2015 ESC Guidelines for the management of patients with ventricular arrhythmias and the prevention of sudden cardiac death: The Task Force for the Management of Patients with Ventricular Arrhythmias and the Prevention of Sudden Cardiac Death of the European Society of Cardiology (ESC) Endorsed by: Association for European Paediatric and Congenital Cardiology (AEPC). *Europace*. 2015 Nov;17(11):1601-87.

- Authors/Task Force Members, Habib G, Lancellotti P, Antunes MJ, Bongiorni MG, Casalta JP, Del Zotti F, Dulgheru R, El Khoury G, Erba PA, Iung B, Miro JM, Mulder BJ, Plonska-Gosciniak

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E, Price S, Roos-Hesselink J, Snygg-Martin U, Thuny F, Tornos Mas P, Vilacosta I, Zamorano JL; Document Reviewers, Erol Ç, Nihoyannopoulos P, Aboyans V, Agewall S, Athanassopoulos G, Aytekin S, Benzer W, Bueno H, Broekhuizen L, Carerj S, Cosyns B, De Backer J, De Bonis M, Dimopoulos K, Donal E, Drexel H, Flachskampf FA, Hall R, Halvorsen S, Hoen B, Kirchhof P, Lainscak M, Leite-Moreira AF, Lip GY, Mestres CA, Piepoli MF, Punjabi PP, Rapezzi C, Rosenhek R, Siebens K, Tamargo J, Walker DM. 2015 ESC Guidelines for the management of infective endocarditis: The Task Force for the Management of Infective Endocarditis of the European Society of Cardiology (ESC) Endorsed by: European Association for Cardio-Thoracic Surgery (EACTS), the European Association of Nuclear Medicine (EANM). Eur Heart J. 2015 Nov 21;36(44):3075-128.

WG officially affiliated to a journal?

NO. Position papers are sent to European Heart Journal and accepted following peer-review.

Sessions

(Proposals for pre-arranged sessions at the ESC 2015 main congress (London):

Symposium	Imaging and myocarditis (accepted)
Case-based symposium	Myocarditis: The Task force criteria in the real world (accepted)
Symposium	Hot issues in myocarditis (rejected)
Symposium	The quest for new therapies for myocarditis (accepted)
Symposium	Unsolved issues in DCM (rejected)
Clinical Seminar	Highlights on cardiomyopathies: what's new? (rejected)
Clinical Seminar	Rare cardiomyopathies: from aetiology to treatment (accepted)
Symposium	Iron, oxidative stress and the inflamed heart (rejected)
Symposium	Metabolic cardiomyopathies - management issues (rejected)
Clinical Seminar	Cardiac amyloidosis (rejected)
Debate	Controversies in the management of HCM (rejected)
Symposium	Update in Dilated cardiomyopathy (accepted)
Clinical Seminar	Towards new therapeutics in cardiomyopathies? (rejected)
Symposium	Neuromuscular Cardiomyopathies (rejected)
Symposium	ARVC (rejected)
Symposium	How to cope with recurrent pericarditis (rejected)
Symposium	Integrated cardiovascular imaging for pericardial diseases. When and how. (rejected)
Clinical Seminar	Alcohol and cardiomyopathy (rejected)
Clinical Seminar	What do we know and what we do not know about Reversible Cardiomyopathies? (accepted)
Clinical seminar	When to suspect a cardiomyopathy in an athlete (rejected)

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Sessions

(Accepted proposals for pre-arranged sessions at the ESC 2015 main congress in London):

3 New supplemental sessions	2015 Pericardial guidelines
Case-based symposium	Myocarditis: The Task force criteria in the real world
Meet The expert (proposal from CHF WG)	Myocarditis
Symposium	The quest for new therapies for myocarditis
Meet the experts-case-based (modified from our proposal)	Rare cardiomyopathies:from aetiology to treatment
Symposium	Update in Dilated cardiomyopathy
New: guidelines in daily practice (case-based)	HCM
New supplemental: proposed by non-ESC subject (South African Heart association and WG21)=1/2	HIV related myocardial and pericardial disease
Modified from our proposal (transversal with Imaging) =1/2	Multi-modality imaging as a help for decision-making, what's new in 2015?
New supplemental: proposed by non-ESC subject (AECPV and WG21)=1/2	Update on cardiovascular tumours
Clinical Seminar	What do we know and what we do not know about Reversible Cardiomyopathies?

Accepted proposals (see above): About 30% of proposals were completely rebuilt from the CPC in collaboration with associations. In all, the WG on Myocardial and Pericardial Diseases had 13 prearranged sessions at the 2015 ESC congress.

The WG also had 8 abstract sessions (see below). Together with 6 sponsored sessions (5 Hand-on tutorial on Fabry's disease repeated each day sponsored by Shire, 1 on Fabry's

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disease sponsored by Genzyme) and 1 Meet the expert on myocarditis (which was proposed from the Heart Failure Association) the WG on Myocardial and Pericardial Diseases had a total of 28 sessions (25 in 2014 at the ESC congress in Barcelona).

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137 Abstracts were accepted in the Topics related to Myocardial and Pericardial disease, as they received a grade >6.5.

Poster sessions (2)	1 Cardiomyopathy, 1 pericardial
Advances in Science (2)	Myocarditis (1); Cardiomyopathy (1)
Rapid Fire (1)	Cardiomyopathy (1)
Best Poster (1)	Cardiomyopathy (1)
Moderated posters (2)	Cardiomyopathy (1); pericardial (1)
Accepted Poster and Abstract sessions at ESC 2015 meeting (London)	

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Other

Task Force(s)

TASK FORCE OF THE WORKING GROUP ON MYOCARDIAL AND PERICARDIAL DISEASE ON: "Myocardial involvement in systemic immune-mediated diseases: diagnosis, management and perspectives for aetiology-directed therapy in isolated inflammatory cardiomyopathy. A position statement of the ESC Working group on Myocardial and Pericardial disease."

AUTHORS:

- WG Nucleus members: Ales Linhart (Vice-chairperson, CZ), Philippe Charron (past-chairman, FR), Yehuda Adler (IL), Aris Anastasakis (GR), Pablo Garcia-Pavia (SP), Massimo Imazio (IT), Karin Klingel (GE), Angelos Rigopoulos (GE), Michael Arad (IL), Antonis Pantazis (UK), Alida Caforio (Chairperson, IT),
- WG Task Group / writing group: Coordination: Alida LP Caforio, (IT), WG Chairperson;
 - o ESC TASK Force experts: Alida LP Caforio, (IT), Michael Boehm (GE), Karin Klingel (GE), Stephan B Felix (GE), Stephan Heymans (NL), Ales Linhart (CZ), Sven Plein (UK)
 - o non ESC TASK Force experts: Carlo Agostini (IT), Yannick Allanore (FR), Urs Eriksson (Switzerland), Eric Hachulla (FR), Marco Matucci Cerinic (IT), Renzo Marcolongo (IT), Valeria Poli (IT).

Internal reviewers: Michael Tendera (Poland), Walker UA (Switzerland), Yehuda Shoenfeld (IL), Perry Elliott (UK), Pepe Zamorano (SP).

The Task Force met twice, a kick-off one-day meeting took place on April 20th at the Municom Center; a second one-day meeting was held on October 22nd at Convitto della Calza, Florence, before the Annual WG annual meeting scientific session opening. The position paper will be completed and submitted to the Eur Heart Journal by the year 2016.

Registry / Survey

The WG on Myocardial and Pericardial Diseases has promoted the Cardiomyopathy pilot study which is part of the EORP. Due to the success of this initiative, the WG on Myocardial and Pericardial Diseases suggested a new long-term registry, approved by the EORP, named "CARDIOMYOPATHY AND MYOCARDITIS REGISTRY", that is ongoing, with sections dedicated to children and to myocarditis, defined according to the 2013 Myocarditis Task Force criteria that were published in another WG of Myocardial and Pericardial Disease Position Paper (Caforio ALP, Pankuweit S, Arbustini E, Basso C, Gimeno-Blanes J, Felix SB, Fu M, Heliö T, Heymans S, Jahns R, Klingel K, Linhart A, Maisch B, McKenna W J, Mogensen J, Pinto Y, Ristic A, Schultheiss HP, Hubert Seggewiss H, Tavazzi L, Thiene G, Yilmaz A, Charron P, Elliott PM. Current state of knowledge on aetiology, diagnosis, management and therapy of myocarditis. A Position statement of the European Society of Cardiology Working Group on Myocardial and Pericardial Diseases. *Eur Heart J* 2013 2013; 34:2636-48).

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What are your perspectives for the next 2 years

List your future projects / business plan

WG EDUCATIONAL PROJECT

The WG on Myocardial and Pericardial diseases designed, in 2014, following to ESC board suggestion, an educational project. In 2015 the WG educational project was advertised. The WG educational project was considered attractive by some Industry sponsors, who signed with the ESC finance dept contracts for a total of 65.000 € (Shire 30K€ + Genzyme 35 K€) of unrestricted grants to fund it. These funds came as additional non-ESC resources in the 2015 Myocardial and Pericardial diseases WG budget. On this basis, the first Webinar on Myocarditis (sponsored by Shire) took place (see above). On the basis of the funds actually secured in the WG budget, next steps for development of the WG educational project are listed below:

1- Planning new webinars: The WG will propose new webinars in 2016 and 2017. In keeping with the educational project, the first one in 2016 (tentatively in spring) will be devoted to the accepted position paper on dilated cardiomyopathy, dealing with definition, diagnostic work-up and etiology-directed therapy. The project has been approved by the Nucleus at the last Nucleus meeting held in Florence on October 22nd, the request form will be sent before the end of this year. The following accepted position papers will become subjects of future webinars to disseminate knowledge.

2- Development of the clinical case portal: The WG nucleus will develop in the next 2 years a new clinical case portal for Myocardial and pericardial diseases, which will be accessible for the WG members (a good educational incentive to become member). This will be the first step to the ESCel Platform. The project has been approved by the Nucleus at the last Nucleus meeting held in Florence on October 22nd.

3- Key message booklet: Again in keeping with the WG educational project, the nucleus will produce a key message booklet, focusing on 2 or 3 WG Position papers published in last 2 years and create a booklet to be distributed at 2016 ESC Congress and the WG annual meeting. Similar kind of documents, generally produced by ESC associations, already exist and are very appreciated by sponsors and delegates. The project has been approved by the Nucleus at the last Nucleus meeting held in Florence on October 22nd.

4- Workshops at WG annual meetings: the WG nucleus will develop the scientific programme of the 13th Annual meeting in Germany in 2016 and the 14th Annual meeting in Denmark in 2017 in collaboration with the local PCO. A minimum of **5 Educational sessions** (called workshops) will be set, where sponsor representative are planned to attend. These workshops will be recorded and used for educational purposes.

WG Position Papers

A new Position paper proposal and Task Force will be proposed to CPG, devoted to "Rare myocardial and pericardial diseases". The project has been approved by the Nucleus at the last Nucleus meeting held in Florence on October 22nd. The request form will be sent before the end of this year. If approved by CPG, the Task Force will develop the paper in 2016 and 2017.

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Prepare your budget

- **List your Income: Please specify amount & purpose (from ESC entities & from Industry sponsorship)**
 - 1) Industry sponsorship: 65.000 € (Shire 30K€ + Genzyme 35 K€) of unrestricted grants to fund the Myocardial and Pericardial diseases WG educational project (see below)
 - 2) ESC subvention: 20 K€
 - 3) possible surplus from 2016 and 2017 annual meetings (to be defined)
- **List your main expenses: Please specify amount & purpose:**
 - 1) Nucleus and Position paper meetings in Florence (October 2015) costs: 20 K€ from ESC subvention. Next Nucleus and Position paper meetings in 2016 (to be deducted from ESC subvention in 2016).
 - 2) Clinical case portal (3800€) from Industry sponsorship.
 - 3) Key message booklet (12000€) from Industry sponsorship.
 - 4) Webinar (9300€) from Industry sponsorship, already done in September 2015, another to be planned temporarily in spring 2016.

• WG budget validated by the ESC Board

DESCRIPTION	FY 2015-2016				ANNUAL BUDGET
	Q1 BUDGET	Q2 BUDGET	Q3 BUDGET	Q4 BUDGET	
INCOME :					
Sponsorship and advertising	77 000				77 000
Profit (loss) sharing and royalties					0
Fi. Sup. from/to other organisation.					0
TOTAL INCOME	77 000	0	0		77 000
EXPENSE :					
Volunteers and consultants travel	-4 000		-7 500	-2 000	-13 500
Seminars costs package	-4 000		-8 000		-12 000
IS and audiovisual subcontracting	-2 500		-2 000	-2 500	-7 000
Other subcontracting					0
Printing and design		-12 000			-12 000
Postage and mailing					0
Miscellaneous					0
Scientific Division support		-3 800		-7 000	-10 800
Fi. Sup. from/to other organisation				20 000	20 000
TOTAL EXPENSES	-10 500	-15 800	-17 500	8 500	-35 300
PROFIT (LOSS)	66 500	-15 800	-17 500	8 500	41700

30 K€ already signed with SHIRE
35K€ under signature with GENZYME
 No surplus from annual meeting agreed

Nucleus & position paper meetings in Florence costs (20.000€)

Dev. of Educ. Programme items:
 -1 Webinars (**9300€**)
 - Clinical case Portal (3800 €)
 -1 Key message booklet (12.000€)

ESC Subvention: 20K€

Any Other Business

N/a

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Provide us a SWOT analysis of your Working Group

Strength

The WG on Myocardial and pericardial diseases is composed by a relatively small (351 members as by August 2015), but very active group of people with a strong interest and a good scientific track record in cardiovascular diseases perceived as rare, complex, poorly understood causes of heart failure, and/or sudden cardiac death particularly in the young.

Weakness

Financial support from ESC and other sources is underpowered to accomplish ambitious scientific research projects, especially in the medium-long term.

Opportunity

There is growing interest in the myocardial and pericardial disease fields both within the ESC as well as in the cardiological community at large and from Industry, due to recent advances in understanding etiopathogenesis and the hope for etiology-based therapy. In this regard the development of the Myocardial and Pericardial Disease WG Educational project could help in gaining visibility for the WG and attract new sponsors.

Threaten

Lack of support from the ESC for WGs and incorporation into other larger bodies, without a specific interest, scientific reputation and expertise in myocardial and pericardial diseases.

Address your recommendations/suggestions to the ESC for the next 2 years

- Maintain independence and scientific mission of WGs and ESC subvention to them.
- Provide new opportunities for funding WG-driven high-quality specific research projects, including multicenter European clinical trials aimed at answering relevant clinical information, but unlikely to be funded by Industry. Facilitate access and provide technical support for application by the WGs to EU research funding programs as well as other funding entities.