



FH Europe

The European FH Patient Network

2019 Business Plan and Work Pack FH Europe Working Group

Requests for resources should be submitted to the Trustee Board by
....(date)

Group 1: Communications

AIM of WORKING GROUP: e.g. to raise awareness and influence decision makers; to support successful organisation of annual network meetings and other events; etc.

Working Group Leader

Contact details (email and phone)

Members of Communications Group (as at 3 November 2018)

Inese Maurina	ParSirdi.lv	Latvia
Gabriele Hanauer-Mader	Chol	Austria
Monica Popescu	FOBAC	Romania
Linnea Blomstroem	FH Sverige	Sweden
Ruth McCafferty	Croi	Ireland

Additional members

Group 1: Communications

- Social Media
- E-Flash
- FH awareness day
- Web site
- Printed media / PR
- Digital materials

This group will be supported by a medical communications agency.



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Group 2: Policy & KOL community building

AIM of WORKING GROUP: e.g. to raise awareness and influence decision makers; to support successful organisation of annual network meetings and other events; etc.

Working Group Leader

Contact details (email and phone)

Members of Policy & Key Opinion Leaders Group (as at November 2018)

Vincent Durlach	Anhet	France
Veronique Lemaître	Anhet	France
Bernard Vercoustre	Anhet	France
Sophie Béliard	Anhet	France
Gergely Jambrik	SZVSN	Hungary
Marzena Romanowska-Kocejko	Stowarzyszenie Pacjentów z Hiperlipidemią Rodzinną w Gdańsku	Poland
Tomasz Kocejko	(as above)	Poland
Andre Miserez	Swiss FH/SGFH	Switzerland

Topics agreed for action in 2019

Group 2: Policy & KOL community building

- HCP identification and key messages
 - Speaker identification
 - KOL identification
- Other networks mapping / Alliance building



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Group 3: Meetings

AIM of WORKING GROUP: e.g. to raise awareness and influence decision makers; to support successful organisation of annual network meetings and other events; etc.

Working Group Leader
Contact details (email and phone)
Group members
as at 3 November 2018

Members of Meetings Group (3rd November 2018)

Mihnea Ionescu	FOBAC	Romania
Florentina Sarbu	BelChol	Belgium
Diana Maxwell	FH Europe	UK

Topics agreed for action in 2019

Group 3: Meetings

- Annual meeting: country responsibility to organise the event, logistics will be supported by agency
- Theme will be suggested by the board
- Speaker will be suggested from the local country where event is organised, approved by the board



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Group 4: FH Europe Strategy

AIM of WORKING GROUP: e.g. sustainability building for the FH Europe network and business planning

Working Group Leader

Contact details (email and phone)

Members of FH Europe Strategy Group (3rd November 2018)

Francesco Fuggetta	ANIF	Italy
Gloria Hastings	GIP-FH	Italy
Askar Faskhutdinov	HLP Patient Organisation	Russia
Gunnar Karlsson	FH Sverige	Sweden

Topics agreed for action in 2019

Group 4. FH Europe Strategy

- Sustainability building, “business planning”
- Funding
- Impact report
- Strategic plan with strategic imperatives
- Bringing in new countries



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Group 5: Cross country assessment

AIM of WORKING GROUP: e.g. to raise awareness and influence decision makers; to support successful organisation of annual network meetings and other events; etc.

Working Group Leader

Contact details (email and phone)

Members of Cross Country Assessment Group (3rd November 2018)

Dorothy Mehnert	CholCo	Germany
Aram Zegerius	-	Netherlands
Krystina Cillikova	. FH	Czech Republic
Theodora Varkonyi-Weisz		Switzerland

Topics agreed for action in 2019

Group 5. Cross country assessment

- Opening discussion forums,
- surveys about Access to Treatment,
- P&R (*needs to be written in full*)
- PSP (*needs to be written in full*)
- Treatment (TX), etc.
- Preparing heat maps

How and when we plan to achieve the above:

No.	What will be done	Who will do it	Completion date
1			
2			
3			
4			
5			
6			
7			

How we will measure outcomes of our activity:

Resources/support required from FH Europe

Estimated financial resource required:

EVENTS:

Room hire –

Audio-visual equipment –

Transport and travel costs (how many people?)

Cost of any out-sourced services

Additional costs (*please specify where possible – e.g. stationery, telephone calls to decision-makers etc.*)

ESTIMATED COST OF WORKING GROUP MEETINGS

(see below for reference)

ORGANISING WORKING GROUP MEETINGS:

- **Virtual meetings**

Cost-free video or audio calling via Skype (<https://www.skype.com/en/>) or Facetime (<https://support.apple.com/en-gb/HT204380>) or WhatsApp (<https://www.whatsapp.com>) are recommended.

Google Hangouts will be phased out in October 2019 and possibly replaced with an alternative.

WhatsApp now makes it easier to start group voice and video calls. Tap the call button in groups or select 'group call' when starting a new call in the calls tab. Group calls support up to four participants.

Other cost-free Voip (Voice over internet protocol) services may be suitable.

Paid teleconferencing: Teleconference call costs may be based on a monthly charge (e.g. GBP10.00). With a number of services, when using a Shared Cost number, everyone dialling into the conference pays for the cost of their phone call.

Note: in the EU mobile phone call charges are capped, but this is not the case for attending an overseas conference, where call costs may be very high.

- **Face-to-face meetings**

Scheduling a meeting may be assisted by using free 'Doodle' online calendar tool (https://doodle.com/en_GB)

Cost of a meeting venue:

Transport costs at economy rate:

Any overnight accommodation that may be required:

Out-of-pocket expenses for light meals, local transport