

EUROPEAN KIDNEY HEALTH ALLIANCE

Internal Rules



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1. Article 1: Internal Rules

These Internal Rules are supplementary and subordinate to the Statutes of the European Kidney Health Alliance (see the statutes, Art. 16), an international not-for-profit organisation incorporated under Belgian law.

The Incorporation Deed of EKHA (15 July 2019) with the Statutes, state that in the event of conflict between the Statutes of Association and the Internal Rules, if any, or any other kind of regulations of the Association, the Statutes shall prevail.

2. Article 2: Membership

2.1 Membership payment timing

The payment of the membership fee is due as follows:

- Full members pay 50% of the fee in the first quarter and the rest at least 1 week prior to the G.A. (see the statutes, Art. 8.2);
- Affiliate members pay the whole membership fee at the beginning of the calendar year.
- As an addition to Art. 8.2 it is also possible for physicians' societies, to change membership fees in case of serious issues at paying the amount as stated in this slide (and determined by the EKHA statutes). Suggestions for exceptions can be made by (mail) dialogue.
- Exceptions can be granted only after approval of the BoD (see Art. 10.1 of the EKHA statutes)

3. Article 3: Additional bodies

EKHA welcomes the involvement of (individuals of) kidney related (non) commercial organisations that have synergies between EKHA activities at EU level, the goals of EKHA and their own lobbying efforts at national and/or international level. These individual organisations can connect to EKHA as members of working groups or engage in more defined collaboration to support the achievement of EKHA's goals by contribution in kind (only non-commercial) and/or funding and collaboration on specific EKHA topics (see the statutes, Art. 9)

To engage in the collaboration as described above, individuals and/or organisations must fulfil the following criteria:

- share goals/ or are related to the work of EKHA;
- have no conflict of interest between their goals and the goals of EKHA;
- have the quality of life of patients as first priority;
- understand that collaboration is based on patients' needs;
- guarantee EKHA's independence at all times;
- is impartial, objective and works in an evidence-based manner;
- act transparently;
- act in accordance to the Code of Ethics (see Annex I).

4. Article 4: Governance

4.1 Term of the Executive Committee

The Executive Committee is appointed for a period of 4 years.

Upon the decision of the BoD it is possible to install a co-chair next to the President. The term of the co-chair is the same as the President. The past president is able to stay for 1 additional year for continuity reasons.

4.2 Supportive network

For the achievement of goals and deliverables EKHA has created several specific groups. These sub commissions meet at least 4 times per year. All sub commissions and affiliates together are called 'the supportive network'.

All members of the supportive network are considered as volunteers (in-kind affiliates) that work under the conditions of the "cooperation agreement volunteer EKHA" as stated in Annex II.

4.3 Declaration of Interest

Potential new members of the BoD and the Working Groups are asked to submit a Declaration of Interest to the EKHA Board of Directors, so that decisions about potential conflicts of interest can be taken collectively rather than left to the individual's own judgement.

5. Article 5: Finance

5.1 Budget process

Before every new calendar year, in Q4, EKHA determines a working budget for the next year based on sources of income, capital and reserves available from past year(s), expenses planned for tasks and activities according to priorities and availability and an increase of reserves planned.

A first draft of the Budget is drawn up by the Treasurer with support of the Association Manager and the Secretariat upon a known Budget template and put on the agenda of a BoD meeting that is scheduled no later than November of the calendar year.

After the approval by the BoD the working budget tasks and activities and the allocated income and expenses will be monitored and adjusted.

The progress of the Budget and the Accounts will be a reoccurring item during the BoD meetings at the end of each Trimester, so that the BoD can have a regular overview of income and expenses planned and received or paid (Budget versus Actual reports upon Budget template, see Annex III)

The budget and the actual reports should include:

- 1) The quotes of services for an event, if organized by EKHA. Once the event is finished, the invoices should match the quotes OR, if different, a short explanation should be given for the difference of foreseen and actual amounts.
- 2) The work done by the three main providers for any extraordinary activity should follow the normal quote-invoice procedure as for point 1.
- 3) The work done by the three main providers for the ordinary activity, as justified with the original quote (approved by the BoD) with their specific tasks and services. Only after 10% additional hours made, the providers will charge these.

5.2 Annual Accounts

The annual accounts of the closing year should include:

- a balance sheet;

- a profit and loss and annexes with breakdowns.

They should be audited before the General Assembly and at the latest before June 30 of the calendar year. After the approval of the BoD, the accounts must be presented at the General Assembly for approval (see the statutes, Art. 15.3). The G.A. should discharge the BoD after the approval of the accounts.

5.3 Invoicing (timing and VAT)

The process for issuing EKHA invoices is as follows:

- The General Manager will request the creation of an invoice to the Secretariat giving all the necessary information: amount, title of the invoice with reasoning, address + VAT number of the recipient.
- The Secretariat, within 2 working days, will issue and send an invoice to the recipient, based on the information and inform the General Manager.
- The Secretariat will be in charge of verifying that the payment is received in due time and, if necessary, of sending reminders. The payment period stands for 30 days. If the payment has not been done, the Secretariat will send:
 - First reminder after 31 days
 - Second reminder after 14 days, including a warning that the amount then is due within a week
 - Third reminder after 7 days
- The General Manager will be informed of any payment problems if the invoice is not paid 10 working days after each reminder dead-line and will follow up, also eventually supporting the Secretariat, if necessary.

5.4 Expenses

EKHA expenses consist of suppliers who provide in services for:

- Association Management
- Organisation and strategy
- Public Affairs
- Management of all members, stakeholders and sub commissions
- Communication
- Legal and accounting
- Event management

5.5 Payment

The process for invoices to be paid by EKHA is as follows:

- The General Manager checks if the invoices are according to agreement and budget;
- Invoices (< € 5000 euro) will be uploaded into the financial system by the secretariat and signed off by the General Manager;
- Invoices (> € 5000) will follow the same process but have to be approved by a countersign by a member of the Executive Committee (Secretary or Treasurer) before they can be paid.

Note: invoices of the General Manager have to be approved by a member of the Executive Committee (Secretary or Treasurer).

PRACTICAL INFORMATION AND GUIDELINES

- 1) All invoices are sent to the Secretariat, the commercial address of EKHA, to the attention of the Management Support Team, 4 rue de la Presse, 1000 Brussels

- 2) The Secretariat, within 5 working days, sends all invoices to the General Manager, after checking formal correctness of the invoice.
- 3) The General Manager checks the correctness of the invoice with regard to the amount and services provided and thus if they are within the approved work plan/budget approved by the BoD. If the amount to be paid is less than €5000 and it is compliant with the agreed work plan and budget, previously approved by the BoD, the General Manager must send the approved/signed invoice within 5 working days, to the Secretariat clearly stating which item of the budget the invoice must be allocated to.
- 4) In case of an amount over € 5000, but still compliant with the agreed work plan and budget, previously approved by the BoD, the General Manager will send the checked/validated invoice to either the Secretary or the Treasurer for their signature, within 5 working days. Full details and reference to the approved work plan and budget, approved by the BoD, must be given to the Secretary or the Treasurer by the General Manager to facilitate the signature.
- 5) Within 5 working days the Secretary or the Treasurer will sign and send back the invoice to the Secretariat, with a written approval to proceed with the execution of the payment.
- 6) In case of an invoice with an amount over €5000 but and NOT compliant with the agreed work plan and budget the General Manager will have to consult with the BoD before the payment process can start. For this purpose, an email approval of the majority of the Board within a strict dead-line is valid.

5.6 Bank Account

The bank account of EKHA has the following mandates:

- Full mandates (no limits to access bank account) for the General/ Association Manager, Treasurer and the Secretary including a bank card for digital banking);
- 2 by 2 mandate (including a bank card for digital banking) for the secretariat which means that they can upload payments into the online bank account system but that the payment is only done after approval of the Treasurer or the Secretary of EKHA (in writing).

5.7 Unrestricted grants

To attract additional funding and at the same time fulfil EKHA's goals, commercial organisation can collaborate with EKHA via one of the support packages (see annex IV). In addition to a support package EKHA also can be supported by an unrestricted grant at the following additional criteria to the ones stated in article 3 above (Additional bodies):

Additional conditions for unrestricted grants:

- We strive for a variety of projects and therefore different funding bodies to minimise conflict of interests;
- A written agreement between funders and EKHA that outlines the nature and amount of the funding as well as the period covered;
- No endorsement or promoting of products, medicines, brands or health services are possible;
- No financial support from companies that are a public health risk or companies that make unsustainable/misleading claims about their products is possible;
- No adverse publicity is possible.

Annex I: Code of Ethics

This code of ethics is a code of behaviour for the governance of EKHA designed to give our members, participants of the additional bodies, supporters and suppliers, guidelines on our business ethics and stance on various controversial matters. The following principles are the basics of EKHA's ethical code.

Integrity and transparency

We work together to achieve specific outcomes. Our behaviour should contribute to our goals, whether financial or organizational. We are honest and transparent in our interaction with other people.

Conflict of interest

Conflict of interest may occur whenever your interest in a particular subject leads you to actions, activities or relationships that undermine the work of EKHA. This includes situations like using your position's authority for your own personal gain. If it turns out you have created a conflict of interest for yourself, the collaboration with EKHA stop.

Accepting personal gifts is not allowed when representing EKHA. Gifts should be handed over to the support office of the association, that will collect gifts to EKHA during the year. At the end of the year, received gifts will be raffled and distributed among the working group members/ambassadors of EKHA.

Justice

We are objective when making decisions that can impact other people. We can justify any decision with written records or examples. When we are wrong in a specific instance, we don't try to cover it up or accuse the other side.

Lawfulness

You are obliged to follow all laws which apply to our organization. Depending on your role and profession, there might be various laws you need to observe. When you're preparing contracts, clauses, disclaimers or online copy that may be governed by law (such as consent forms), please ask verification from external legal counsel before finalizing anything.

Inclusive

We welcome and support people of all backgrounds and identities. This includes, but is not limited to members of any sexual orientation, gender identity and expression, race, ethnicity, culture, national origin, social and economic class, educational level, colour, immigration status, sex, age, size, family status, political belief, religion, and mental and physical ability. We all depend on each other to produce the best work we can. Our decisions will affect clients and colleagues, and we take those consequences into account when making decisions.

Respectful

We won't agree all the time, but disagreement is no excuse for disrespectful behaviour. We will experience frustration from time to time, but we cannot allow that frustration become personal attacks. An environment where people feel uncomfortable or threatened is not a productive or creative one. We do not insult or put down others. Harassment and exclusionary behaviour aren't acceptable. This includes, but is not limited to: threats of violence, discriminatory jokes and language, sharing sexually explicit or violent material via electronic devices or other means, personal insults, especially those using racist or sexist terms, unwelcome sexual attention, and advocating for, or encouraging, any of the above behaviour.

Patient and courteous

We embrace different approaches and resolve differences in opinion with our colleague's one-on-one as far as possible and not in the presence of a whole group. Repeated harassment of others in general, if someone asks us to stop something, we stop. When we disagree, we try to understand why. Differences of opinion and disagreements are mostly unavoidable. What is important is that we resolve disagreements and differing views constructively.

Competence and accountability

We all need to put a healthy amount of effort in our work. Not just because we're all responsible for the organisation's success, but also because slacking off affects our colleagues. We take responsibility for our actions. We all make mistakes or need to make tough decisions and it's important we own up to them.

Annex II: Cooperation agreement volunteer EKHA

EXAMPLE AMBASSADOR

Name of the volunteer:

Date of birth:

Residence and country:

and

the European Kidney Health Alliance (EKHA)

declare to enter into a cooperation agreement, whereby the volunteer will volunteer for EKHA. The following agreements have been made:

1. Voluntary Activities

The volunteer performs voluntary activities for EKHA in the Ambassador Group.

2. Indicated time of work

Attending appr. 4 Ambassador meetings per year (1,5 hour each), the overall approx. time spent each month is 2 hours.

3. Mutual agreements

Who can attend the ambassador group:

- Kidney patients, next of kin
- Influencers/celebrities with a strong link (or own experience) with kidney disease
- Kidney donors
- Any person who can support the group due to his/her professional role

Activities

- Sounding board for the other EKHA working groups
- Reflection on the objectives of the other EKHA working groups and securing the patients voice and point of view
- Inventory of different patient groups
- Identify the most important unmet needs and disparity in needs, help people taking care of these needs and elevate their quality of life
- Create awareness for the different patient needs by being vocal in the EU political field
- The burden for kidney patient lies in social and psychological needs. We therefore focus on the biomedical part (effects of therapies, drugs and devices) of the disease since ESKD patients are for a huge part of their live 'in between dialysis'
- Community building and linking initiatives

EKHA expects the following from the Ambassador:

- Your opinion on how to tackle Chronic Kidney Disease as an experience expert
- Dissemination of EKHA actions via your own communication channels
- Help with the expansion of the ambassador community
- Officially representing EKHA at meetings (conferences, EU committee)

4. Remuneration and compensation

The volunteer does not receive any monetary reward for the work to be performed by you. Travel and accommodation costs for EKHA activities are reimbursed. You are entitled to reimbursement of the costs actually incurred.

5. Liability

The volunteer is not personally bound by the obligations of the association. Their liability shall be limited to the execution of their voluntary assigned tasks and faults committed in the (non) performance of their duty and tasks. EKHA is not accountable for statements of the volunteer that are not in line with EKHA policy, goals and the power and liability as described in the Incorporation Deed of 15 July 2019, chapter 11.1

6. Conflict of interest

In case a volunteer has a direct or indirect interest of a patrimonial nature, which is conflicting with the interest of EKHA or an operation falling within the powers of the General Assembly or Board of Directors it shall notify the conflict of interest to the Board of Directors and provide all facts material to the conflict as soon as possible and accordingly to paragraph 18.2 of the Incorporation Deed of 15 July 2021

7. Confidentiality statement

During the performance of the work, the undersigned volunteer will be given access to privacy-sensitive special personal data. The undersigned undertakes to maintain strict confidentiality with regard to this information. If a security incident is discovered in which personal data may have been leaked or lost, the undersigned will immediately (and in any case within 24 hours) notify EKHA by telephone or e-mail.

8. Nature of the agreement

This agreement is not an employment agreement as meant in the Civil Code. The relationship between EKHA and the volunteer is not an employment relationship.

9. Duration and end of the cooperation agreement

The cooperation agreement comes into effect on

The parties can terminate the agreement at any time by mutual agreement, subject to a notice period of one month. Immediate termination without notice will take place if there is an urgent reason.

10. Other

The volunteer declares to have truthfully provided all relevant information to EKHA.

The cooperation agreement has been drawn up and signed in duplicate. The volunteer has received a copy of this agreement.

Signatures for agreement

Place and date:

Place and date:

Volunteer

On behalf of EKHA
Raymond Vanholder, EKHA President

Annex III: Budget Template

Budget versus Actual report for BoD Monitoring								
	01/01/2022		25/10/2022		Excl. VAT 10/05/2022	Excl. VAT 25/10/2022	Excl. VAT 25/10/2022	Incl. VAT 25/10/2022
Income	Provisional budget	New provisional budget	Real Budget	Still to be received	Expenses Annual Budget	Budget adjustment	Actual (Spent)	Actual (Spent)
Fees								
Member fees	94,025.00	95,025.00	95,025.00	0.00	Association Management (BDL)	68040	-1890	41580
Associated Member	15,483.75	21,109.35	21,109.35	0.00	Consultants (Interel)	79480	1290	55566.64
Other fees	0.00	0.00	0.00	0.00	Secretariat: Triumph	32400	900	24750
Private donation	0.00	25,000.00	25,000.00	0.00	External Support: Interns	1572		1411.11
					External Support: legal	1000		0
					External Support: finance	3000	381.04	3381.04
Sponsoring					Bankaccount	500	-433.67	66.33
Support packages	117,500.00	155,416.67	155,416.67	0.00	Microsoft licence	265	102.2	367.2
NCD Call	0.00	10,150.00	10,150.00	0.00	Website development	400		400
Madrid Round Table	0.00	32,500.00	25,000.00	7,500.00	Website annual hosting	400		400
					Chairman	1500		927.18
Capital and Reserves invested	51,177.42	51,177.42	51,177.42	0.00	Organisation BoD costs	0		1939.7
					ECDA Membership	4000		4000
					Events			
Total	278,186.17	390,378.44	382,878.44	7,500.00	Forum + General Assembly	50000	-3,896.46	46103.54
					Novartis Round Table	21195		3090
					Industry Network Meeting	10000		0
					Unforeseen			
Current Assets in Bank (25/10/2022)	114,664.73				World Kidney Day Event	15000	-2,527.29	12472.71
Capital and Reserves (surplus 2021)	51,177.42				Application Operating Grant	4000		4000
					Ukraine	1377.5	-0.5	1377.5
					Lunch with MEPs	0		142.11
					NCD call	10150		10150
					Madrid round table	32500		10039.7
					15th Anniversary	9395.34	-230.50	9164.84
					VAT return			-649.53
						346,174.84	-6,305.18	231,329.60
								265,573.58

Annex IV: Support Packages

For commercial organizations EKHA has the following different support packages to engage in collaboration:

BRONZE PACKAGE – Annual costs: 12,5K

1. Sponsor of the annual kidney forum:
 - Invitation for 1 representative to attend and possibility to raise 1 question in the chat.
 - Company logo and recognition as “Bronze Sponsor” in outgoing “Save the Date”, invitations, online registration pages, program, general marketing.
 - Company recognition on event page of EKHA’s website.
 - Electronic copy of event materials.
2. Monthly updates via EKHA newsflashes
3. Annual industry network event

SILVER PACKAGE – Annual costs: 20K

1. Sponsor of the annual kidney forum:
 - Invitation for 2 representatives to attend European Kidney Forum and possibility to raise 2 questions in the chat.
 - Company materials (brochures, etc.) to be displayed (1 item) in the event pack that will be sent to participants ahead of the meeting.
 - Company logo and recognition as “Silver Sponsor” in outgoing “Save the Date”, invitations, online registration pages, program, general marketing and introductory and concluding presentation slides.
 - Company recognition on event page of EKHA’s website.
 - Electronic copy of event materials.
2. Monthly updates via EKHA newsflashes
3. EKHA working group membership + General Assembly attendance as an observer
4. Annual industry network event

GOLD PACKAGE – Annual costs: 30K

1. Sponsor of the annual kidney forum:
 - Invitation for 3 representatives to attend European Kidney Forum and possibility to raise 3 questions in the chat.
 - Company materials (brochures, etc.) to be displayed (up to 3 items) in the event pack that will be sent to participants ahead of the meeting
 - Verbal recognition during event.
 - Company logo and recognition as “Gold Sponsor” in outgoing “Save the Date”, invitations, online registration pages, programme, general marketing and introductory and concluding presentation slides.
 - Possibility to invite up to 2 journalists to the event
 - Company recognition on event page of EKHA’s website.
 - Electronic copy of event materials.
 - Post-event debriefing meeting with EKHA president.
2. Monthly updates via EKHA newsflashes
3. EKHA working group membership + General Assembly attendance as an observer
4. Thematic webinar (organisation costs excluded)
5. Annual industry network event

UNRESTRICTED GRANT IN ADDITION TO SUPPORT PACKAGES:

- Tailored industry project that synergises with EKHA goals
- Funded by an unrestricted grant to be further determined between EKHA and the concerned organisation.