



Farma ter Verantwoording

Pharmaceutical Accountability Foundation

Public Policy Plan 2022-2024

16 June 2022

Table of contents

I. GENERAL DESCRIPTION	3
I.1 Objective	3
I.2 Specifications	3
I.2 Reason for incorporation	3
I.3 Mission	3
I.4 Vision	4
II. GOALS	5
III. POSITIONING	6
III.1 Positioning	6
III.2 Target groups	6
III.3 Partners	7
IV. STRATEGY	8
IV.1 Pull strategy	8
IV.2 Push strategy	8
V. ACTIVITIES	9
VI. GOVERNANCE	10
VI.1 Administration	10
VI.2 Advisory Board	10
VI.3 Codes	11
VI.4 Committee of Recommendation	11
VI.5 Volunteers	12
VI.6 Staff	12
VI.7 Office	12
VII. FINANCE	13
Budget/multi annual planning	13
Fundraising	13
Financial power of attorney	14

I. GENERAL DESCRIPTION

I.1 Objective

The objective of this Policy Plan is to inform the general public, professionals, partner organisations, stakeholders, relevant authorities and possible funders about the policy, governance, funding, and activities of the Foundation.

I.2 Specifications

The stichting Farma ter Verantwoording (Pharmaceutical Accountability Foundation) has the following specifications:

- Official Name (Dutch): **Stichting Farma ter Verantwoording**
(English name: **Pharmaceutical Accountability Foundation**)
- Address: Prins Bernhardstraat 1, 5571 GC Bergeijk, the Netherlands
- Email address of the Foundation: [info\[at\]farmaterverantwoording.nl](mailto:info@farmaterverantwoording.nl)
- Contact for ANBI procedure: [bestuur\[at\]farmaterverantwoording.nl](mailto:bestuur@farmaterverantwoording.nl)
- Website: <https://www.farmaterverantwoording.nl> (NL),
<https://www.pharmaceuticalaccountability.org> (English)
- Chamber of Commerce registration number: 72078839
- RSIN/tax number: 858976808
- SBI code: 94997 - Other advocacy

The Pharmaceutical Accountability Foundation (hereinafter 'the Foundation') is a Public Benefit Organization (ANBI) so that it can pay for its activities through donations and grants. The Foundation is not-for-profit and will spend at least 90% of the funds received on the Foundation's objective.

I.2 Reason for incorporation

The Foundation was founded on 4 July 2018 by committed lawyers, health professionals and researchers that aim to encourage the pharmaceutical industry to make medicines better available and more affordable to everyone.

The specific reason for its creation was that among the network of Dutch organisations tackling excessive prices of medicines, there was not yet an organisation that can/wants to achieve this through legal procedures.

I.3 Mission

The mission of the Foundation is to ensure that medicines and other medical technologies are available, affordable, and accessible to everyone. In this context, the Foundation values fair pricing and distribution in line with binding and non-binding national, European, and international legal and human rights standards.

The Foundation achieves its mission by providing general information and advice to public authorities, policy makers, social bodies, educational institutions, pharmaceutical industry organisations and the general public. If needed, the Foundation may also consider taking legal action against pharmaceutical companies that charge excessively high medicine prices.

I.4 Vision

The Foundation believes in a world in which safe and effective medicines and other medical technologies are available, affordable, and accessible to everyone.

The Foundation wants to contribute to a society where the accessibility and affordability of safe and effective medicines and other medical technologies are guaranteed, as prescribed by the human rights to health, life, and access to essential medicines. This encompasses a society in which medicines and other medical technologies are available and affordable for everyone who needs them regardless of the nature of illness, ability to pay, or place of residence.

II. GOALS

The Foundation pursues the following long-term goals:

1. Pharmaceutical companies are **transparent** about the price structure and development costs of their medicines and medical technologies.
2. By means of case law and/or legislation it is established that pharmaceutical companies have a social and legally binding **duty of care** towards patients and society.
3. Pharmaceutical companies behave in a **fair and socially responsible way**, for example, by no longer setting excessively high prices for medicines and other medical technologies.
4. Pharmaceutical companies charge **fair prices** for their products that are affordable for health systems and patients, and at the same time provide sufficient incentives for innovation and the production of medicines.¹

¹ WHO definition: a 'fair' price is one that is affordable for health systems and patients and that at the same time provides sufficient market incentive for industry to invest in innovation and the production of medicines. <https://www.who.int/news-room/q-a-detail/medicines-fair-pricing-forum>

III. POSITIONING

III.1 Positioning

The Foundation studies the problem of excessive medicines prices, the legal system that enables this, and the resulting impact on patients and the healthcare budget. The Foundation publishes the findings on its website, informs the general public and stimulates the debate around these problems through case reports, publications, and consultations.

The Foundation is primarily committed to the general and societal importance of affordable medicines and other medical technologies.

In concrete terms, this will bring benefits for patients who need excessively priced medicines, and for health insurers and hospitals that have to pay for or provide these specific medicines to patients. Lowering the price levels should also lead to a reduction in health care costs or health insurance premiums for citizens.

Reduced prices of medicines and other medical technologies in the Netherlands are likely to attract attention in other European countries and beyond. To this end, the Foundation cooperates with similar initiatives and organisations in Europe and the rest of the world.

III.2 Target groups

To achieve its objectives, the Foundation targets the following groups:

- Pharmaceutical companies.
- Government
- Parliament
- Health care insurers
- Hospitals
- Health Professionals and their professional associations

The Foundation holds **pharmaceutical companies** to account by pointing at the principles and responsibilities under human rights, due diligence, ethical norms, codes of conduct and legislation. It opts for the use of legal proceedings as a last resort. This may include legal proceedings based on tort law, human rights law, patent law, competition law and other legal regimes.

The Foundation studies how policies of national **governments** and the EU commission influence the Foundation's objectives. The Foundation promotes policies that will make medicines more affordable. If needed, the Foundation works with partners to lobby these entities, for example by bringing specific cases or pointing at the negative impacts of such policies.

The Foundation studies national and European legislation, and how this affects the pharmaceutical industry and our objectives. If needed, the Foundation works with partners and networks to influence legislation in national or EU **Parliaments**.

The Foundation works with **healthcare insurers** and **hospitals** to obtain information about excessively priced medicines, to help achieve more affordable medicine prices, and if needed to claim back excessive profits and undo displacement of health care costs by excessively priced medicines.

The Foundation works with **health professionals** and **professional associations** to obtain information about access problems, discuss possible solutions and to develop campaigns to achieve more affordable medicines.

III.3 Partners

To achieve its objectives, the Foundation works closely with a number of partners.

In the Netherlands, we collaborate with Wemos, the Netherlands Medicines Network, patient and professional organisations, universities, student organisations, hospitals, and health insurers.

At international level, we work with the European Alliance for Responsible R&D and access to medicines, and other NGOs that also want to promote access to medicines or monitor/influence pharmaceutical companies.

Since the Corona pandemic, we have been working with 5 other NGOs to promote a more equitable global distribution of Covid-19 vaccines and therapeutics (CIFA project), and monitor the producers of covid-19 vaccines and therapeutics regarding their compliance with their human rights responsibilities.

All partners are committed in one way or another to increasing the accessibility and availability of medicines and therapies. The specific added value of the Foundation is to conduct research and legal procedures.

The Foundation is in favour of cooperation structures, but it will only deal with those activities which are in line with their own stated goals and ideals.

IV. STRATEGY

The Foundation uses both a push and a pull strategy. Through legal action the pharmaceutical industry is pushed towards measures, and through public opinion the pharmaceutical industry is pulled towards measures.

IV.1 Pull strategy

The Foundation **provides information** about pharmaceutical companies about how they respect their duty of care, and the right to health and life of the patient, as recognised in various human rights treaties (including ICESCR and ECHR) and the Dutch Constitution.

An example of this is the 'Fair Pharma Scorecard', where pharmaceutical companies are rated on the implementation of their duty of care in developing, producing, pricing and equitably making available vaccines or therapeutics for use in Covid-19 (formerly named the Good Covid-19 Company Practices project).

IV.2 Push strategy

The Foundation opts for the use of **legal proceedings** when necessary. The Foundation may conduct legal proceedings on the basis of tort law, human rights law, patent law, competition law and other legal regimes.

Examples are the CDCA Leadiant case where the Foundation complained to the Dutch Competition Authority about a 500-fold price increase, and the liability letter sent to AbbVie for the excessive profit of nearly €1 billion on Humira, and consequent displacement of health care costs in the Netherlands.

V. ACTIVITIES

The Foundation shall endeavour to achieve its objectives by all appropriate means, including through the provision of information and advice, external communication, fundraising and the conduct of legal actions.

The activities are determined on the basis of the Foundation's objectives, as set out in the policy plan and specific action plans.

In order to contribute to the above ideals and goals the Foundation will develop the following activities in 2022 and beyond:

1. Provide general information and advice to governments, policy stakeholders, the pharmaceutical industry, and the public, for instance through our website, presentations and organising webinars.
2. Further develop awareness of the activities and objectives of the Foundation among the wider public, including through social media posts, articles, and webinars.
3. Maintain and expand the Foundation's messages through the (inter)national media.
4. Research and investigate medicines and other medical technologies in which the pharmaceutical company exhibits ethically and socially unacceptable behaviour, and where possible develop the right legal process/strategy.
5. Deepen our analysis of the Human Rights Responsibilities of Pharmaceutical Companies, and monitor their adherence in the Fair Pharma Scorecard project (formerly the Good Covid-19 Company Practices project).
6. Generate more attention for the ethically and socially unacceptable behaviour of the pharmaceutical industry by regularly reporting news about legal proceedings towards pharmaceutical companies (through media attention).
7. Creating pressure towards pharmaceutical companies in the field of pricing and ethically and socially unacceptable behaviour.
8. Conduct research into medicines with excessively high prices through tipsters, literature study, theses, networks of investigative journalists, meetings, consultation with stakeholders and interest groups, and, if necessary, discussion with pharmaceutical companies.
9. Create documents, factsheets and information material for the general public, stakeholders, and the media.
10. Follow-up enforcement decisions by ACM on our former cases, such as the complaint against CDCA Leadiant.
11. Conduct legal proceedings on excessively priced medicines on the basis of tort law, human rights law, patent law, and other legal possibilities.
12. Collaborate with like-minded groups in other European countries on cases under consideration.
13. Explain and expose such cases in the media, on the website and at seminars.
14. Obtain financial support through donations, crowdfunding and applying for grants.

VI. GOVERNANCE

VI.1 Administration

The Foundation is led by a board of 4 members:

- Chairperson: Wilbert Bannenberg, MD, MSc (CHDC), MSc (Epid) [voorzitter\[at\]farmaterverantwoording.nl](mailto:voorzitter[at]farmaterverantwoording.nl)
- Treasurer: Hans Smits, MSc, [penningmeester\[at\]farmaterverantwoording.nl](mailto:penningmeester[at]farmaterverantwoording.nl)
- Secretary: Tegan Insoll, LLM, [secretaris\[at\]farmaterverantwoording.nl](mailto:secretaris[at]farmaterverantwoording.nl)
- Member: Sabina Voogd, MSc, [sabina\[at\]farmaterverantwoording.nl](mailto:sabina[at]farmaterverantwoording.nl)

The board can be reached via [bestuur\[at\]farmaterverantwoording.nl](mailto:bestuur[at]farmaterverantwoording.nl)

The board meets monthly, and works entirely voluntarily.

There is a limited reimbursement of travel expenses incurred and communication costs.

VI.2 Advisory Board

The Foundation has an Advisory Board that advises the Board on request and unsolicited. The Advisory Board also checks the annual reports, projects and related budgets and has a joint meeting with the board at least once a year about the strategy and policy plans to be implemented.

The Advisory Board currently consists of 10 members:

- Prof. Brigit Toebes, PhD, Chairperson of the Advisory Board. Professor, health law in an international perspective, University of Groningen. Co-founder Global Health Law Groningen Research Centre
- Ellen 't Hoen, LLM, PhD, Lawyer and Director, Medicines Law & Policy
- Prof. Huub Schellekens, PhD, Emeritus Professor of Pharmaceutical Biotechnology, Utrecht University
- Jennifer Sellin, LLM, PhD, Assistant Professor, International and European Law, Maastricht University
- Katrina Pehudoff, LLM, PhD, Assistant Professor and Co-Director of the Law Centre for Health and Life, Faculty of Law, University of Amsterdam, Netherlands
- Tom Buis, MSc, Global Health Advocate, Wemos
- Ella Weggen, LLM, Global Health Advocate, Wemos
- Edwin de Voogd, MSc, economist
- Richard van Slobbe, MPharm, pharmacist
- Anna Laskai, LLM, PhD, pharmaceutical criminologist, Utrecht University

The Advisory Board can be reached via: [RvA\[at\]farmaterverantwoording.nl](mailto:RvA[at]farmaterverantwoording.nl)

VI.3 Codes

The Foundation complies with the guidelines of the Dutch Tax Authority to be a Public Good Organisation (ANBI).²

The Foundation adheres to the following codes of conduct and guidelines:

- Recognition Scheme of 'Charities Netherlands' (Goede Doelen NL).³
- Code of Good Governance, Cooperating Trade Associations Philanthropy (SBF).⁴
- Financial Management Charity Directive.⁵
- Directive 650 and Directive C2 (part of guidelines for the annual report of the Annual Report Council) and recommendation Application Directive 650 'management and administration cost allocation'.

All staff, advisors and volunteers directly involved in our Foundation must sign a Conflict-of-Interest statement.

All staff, advisors and volunteers must also meet the integrity requirements of ANBI:⁶

- The institution and people directly involved must not incite hatred or the use of force.
- Directors, executives and publicly appearing spokespersons should not have been convicted for this in the past 4 years.

If the Foundation (or the Dutch Tax Authorities) have reason to doubt the integrity of a director, advisor, or volunteer, it may ask for a Certificate of Conduct (VOG).

VI.4 Committee of Recommendation

In order to increase support in society and for reasons of publicity, a Committee of Recommendation has been established. It currently lists the following persons:

- Em. Prof Dr Andre Knottnerus, former chair NL Health Council and National Science Board
- Dr Prisca Zwanikken MD
- Prof Dr Gerrit van der Wal, MD, former inspector general / CMO
- Prof Dr Pim van Gool, Neurologist, former chair of the NL Health Council
- Em. Prof Dr Flora Haaijer-Ruskamp
- Gilles de Wildt, GP, ass professor Global Health, Birmingham University
- Chris Oomen, pharmacist, former DSW Board chair

2

https://www.belastingdienst.nl/wps/wcm/connect/bldcontentnl/belastingdienst/zakelijk/bijzondere_regelingen/goede_doelen/algemeen_nut_beogende_instellingen/aan_welke_voorwaarden_moet_een_anbi_voldoen/

³ <https://www.goededoelennederland.nl/sector/verantwoording-en-toezicht/erkenningregeling-goede-doelen> Note: PAF is not yet a recognised member of 'Goede Doelen NL'

⁴ <https://www.goededoelennederland.nl/system/files/public/Sector/150715%20SBF%20Code%20Good%20Government.pdf>

⁵ <https://www.goededoelennederland.nl/system/files/public/Bedrijfsvoering/1706%20Directive%20Financial%20Management%20Good%20Targets.pdf>

6

https://www.belastingdienst.nl/wps/wcm/connect/bldcontentnl/belastingdienst/zakelijk/bijzondere_regelingen/goede_doelen/algemeen_nut_beogende_instellingen/aan_welke_voorwaarden_moet_een_anbi_voldoen/integriteitseisen

VI.5 Volunteers

- The Foundation works with volunteers in organised projects with specific job descriptions or terms of reference.
- Volunteers register via a registration form, motivation letter and CV. This also includes a Conflict-of-Interest statement. If necessary, references and a certificate of conduct (VOG) can be requested.
- After approval by the Board, volunteers are offered a volunteer agreement containing their rights, obligations, confidentiality agreements, and information about our insurances.
- Volunteers have regular conversations with their supervisor(s).
- Volunteers can receive compensation for costs incurred according to legal standards.

VI.6 Staff

- The Foundation currently employs the following staff:
 - Project Coordinator (pharmacist)
 - Fair Pharma Scorecard Researcher (lawyer)
- Other staff may be hired on short-term contracts

VI.7 Office

- No physical office is envisaged for the Foundation. The Foundation makes as much use as possible of home offices and meeting rooms of support organisations.

VII. FINANCE

The Foundation is recognized as a (large) ANBI Foundation by the Dutch Tax Authority. In achieving its objectives, the Foundation is financially dependent on grants, donations, inheritances, bequests, and crowdfunding. A donation button is offered on the website.

The Board is bound to ensure that funds and grants are >90% spent on the formal objectives set out in the articles of association.

In practice, this means that funds are mainly spent on staff, legal advice, court and litigation costs of the legal proceedings being planned or conducted. There are also costs for the website, organising activities, research, travel costs, insurance, and bank charges.

The Foundation employs a project coordinator, and a researcher. These functions are paid from the grants obtained.

Board members, and members of the advisory board, work pro-bono. The Foundation may grant a volunteer allowance, which may be returned to the Foundation as a gift. Necessary expenses incurred (e.g. travel expenses) can be reimbursed by means of signed declaration forms.

The Foundation's lawyers work partly pro bono, and partly at an NGO rate.

Activities are organised with and by volunteers.

Budget/multi annual planning

Cost Budget FtV/PAF 2022-2024			
	2022	2023	2024
Expenses			
Personnel costs	€ 85.600	€ 115.000	€ 115.000
Organisational costs	€ 2.250	€ 5.000	€ 5.000
Communication and Website	€ 16.600	€ 25.000	€ 25.000
Project costs	€ 75.000	€ 75.000	€ 75.000
subtotal expenses	€ 179.450	€ 220.000	€ 220.000

Fundraising

The Foundation raises its funds from various sources:

1. Individuals who donate to the Foundation without obligation, e.g. via the donation button on the website: <https://www.pharmaceuticalaccountability.org/support-us/#donate>
2. Grants from private non-profit organisations and public institutions (e.g. financing mechanisms of the Dutch and European institutions)
3. The Foundation proactively searches for philanthropists (without conflicts of interest) who want to financially support the aims of the Foundation

The Foundation wants to diversify its financial sources as much as possible. This means that in the long term we want to ensure that individuals do not sponsor more than 25% and that individual organisations do not sponsor more than 50% of the budget.

Donations from the pharmaceutical industry or related institutions are not accepted. On a case-by-case basis, any potential source of funding is examined on the basis of the Foundation's internal policy for potential conflicts of interest with the Foundation's vision, mission, and working method.

The Foundation's financial resources are stored in bank account NL77ABNA0824948866 (BIC: ABNANL2A or ABNANL2AXXX) in the name of 'Stichting Farma ter Verantwoording'.

Financial power of attorney

The articles of association stipulate that none of the directors may have the account independently: the Treasurer and Chairperson are only jointly authorised to dispose of the bank accounts of the Foundation.

For the Treasurer, a power of attorney has been agreed with a maximum of €1000 for payment of accounts sent to the Foundation that correspond to the budget or are the result of previous administrative decisions.

Above this limit, the treasurer needs permission from the Chairperson.