

# "From Testing to Targeted Treatment Program (FT3)" Governance

Updated September 2021



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#### **Preamble**

The "From Testing to Targeted Treatment" Program, is a nonprofit global initiative hosted by The Synergist and managed in collaboration with its members.

This Program, established in 2020, is an independent nonprofit global coalition, hosted and managed by The Synergist. Providing a precompetitive and neutral environment, the Program seeks to have a balanced representation of stakeholders to ensure transparency, inclusiveness, and credibility. The Program also seeks to be a catalyst and accelerate and support other initiatives working towards the same goal, e.g. medical societies, patient organizations, etc.

Stakeholders include individual patients, carers, patient advocates, patient organization representatives across diverse disease areas, healthcare professionals and medical societies, industry, regulators, payors, HTA bodies, other professional organizations and other groups/alliances in PM are also invited to ensure the diversity of perspectives, create synergies and deliver better public health outcomes.

The purpose of this document is to explain the Program's governance structure. It also depicts how the Program operates, and how it makes operational and strategic decisions on a day-to-day basis.

Ensuring expertise, commitment and agility are key principles for this Program, thus the governance structure should always be interpreted respecting these principles. Additionally, members are asked to review the governance structure with the long term needs of the Program in mind.

# Purpose: Make PM the new normal, starting with cancer and testing

Precision Medicine (PM) can transform lives, but its potential benefits have not yet been fully realized. Today, precision medicine - a rapidly evolving form of medicine, which utilizes individual biological characteristics ranging from genes to cells to identify a personal, targeted treatment and/or preventive diagnosis, moving away from the prevalent "one size fits all" paradigm - is rapidly changing and fragmented. Efforts to expand it are piecemeal and disconnected. Best practices are hard to identify, and lack of standardization on national and global levels is a challenge. Patients are often unaware that better treatments may exist, and are not able to discuss these options with their doctors. Even where treatments are available, barriers to access may prevent that treatment from being offered to patients. Healthcare professionals may need support in interpreting data or in making clinical decisions. As a result, patients do not benefit from optimal treatment, with a health, societal and economic impact.

We believe that all patients deserve equal access to the best treatment for them. The From Testing to Targeted Treatment Program (FT3), established in 2020, is a global, open, and collaborative multi-stakeholder program. We bring together diverse stakeholders and activities to build synergies and accelerate pragmatic efforts to make PM an accessible reality for all patients who could benefit from it, starting with cancer and testing. We use a co-creation approach, building with patients for patients. We aim to accelerate the benefits of PM by bringing together and building on existing learnings and good practices to generate better evidence, create awareness and build the conditions for better access to precision medicine in oncology and beyond.

## **Expected outcomes**

The Program aims to deliver on the following priorities:

- 1. Support the **development of data & evidence** to demonstrate the benefits of PM on patient outcomes and **put in place a data governance structure.**
- 2. **Build the value case for PM** and **raise awareness** to increase support & resourcing, starting with proven clinical areas.



3. Provide education and tools to support patient empowerment and informed decision-making. Help patients enquire about the appropriateness of targeted treatment, and equip healthcare professionals with the resources they need to better support their patients.

Transversal priorities:

- 4. Create favorable conditions for PM: **Build a global multi-stakeholder network and community**, **unify and amplify existing efforts**, and facilitate collaboration to **address systemic barriers to equitable patient access** to targeted medicine.
- 5. Build a world-class governance and the foundation for trust, credibility, agile growth, and impact.

During the lifecycle of the Program, the Program Board may decide to modify the expected outcomes as needs evolve.

#### **Key Principles**

The following principles are founding principles above any other governing rule or policy.

#### Governance for inclusion and agility

Only a partnership across all major stakeholder groups can effectively address this issue. Based on this belief the participation of founding partners representing industry and patient advocacy groups was secured. In addition to this, there is an ongoing effort to seek and add new members from the regulatory, medical, non-profit and academic sectors and beyond who have an interest, expertise in and impact on the different aspects of precision medicine.

The Program seeks to have balanced representation from stakeholders to ensure transparency, inclusiveness, diversity and credibility. This approach fits the credo that only a balanced inclusion of all stakeholders, also reflected in decision-making structures and agile operations, deliver results.

#### Commitment and expertise

Program Members invest in a collaborative platform that will deliver tools, methodologies and support the Program and the issue openly beyond the Program's membership. The Program's membership is based on expertise and commitment to building the conditions for better access to personalized medicine or precision medicine (PM), starting with cancer and testing, inside and outside of member organizations.

Membership in this initiative also represents a duty of loyalty and commitment to actively contribute expertise and resources in helping to realize the mission of the Program. The Program's members act as exemplary cases for other organizations and stakeholders to follow.

When signing up for membership, organizations are committing to building and adopting outputs developed by the Program and help deploy it across all other stakeholders.

#### Collaborative leadership

The Program is non-competitive as a core principle and does not exist to promote the interests of any specific organization, their brands or products. Members must always work for the interest of the common goal, leaving individual interests at the door.

There should be a balance between what each Member brings to and takes away from the collaboration. Deliverables should be defined that create value for all participants. Resource sharing is a value exchange. In general, tools and information produced should be open and accessible to anyone. At the same time, we can be adaptive and recognize specific needs or constraints.

Finally, in committing to the common goal, Members recognize that the Program's role is to be a catalyst and support other initiatives working towards the same goal.



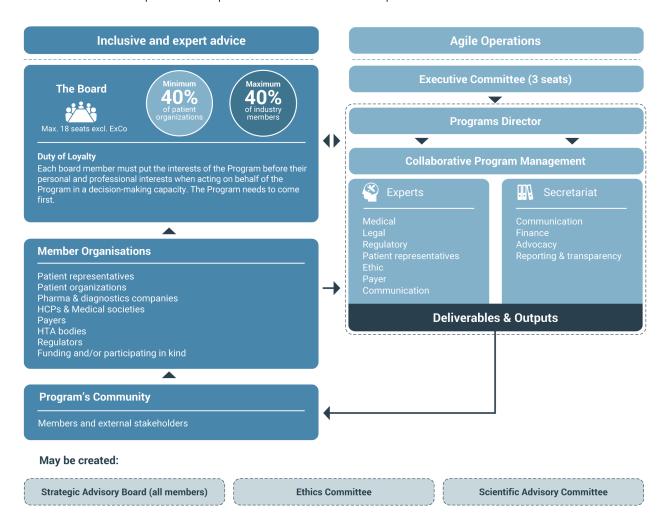
#### Nature of the organization

The Program membership does not constitute a legal entity between the Members, nor makes a Member the agent or representative of another Member, unless expressly stated otherwise. The Program is hosted by The Synergist and formed by bilateral contracts between The Synergist and individual members. (The Synergist is described in Annex 1).

#### **Draft organization structure**

The Program is governed by a Board, which represents members and takes the major strategic decisions for the organization.

Day-to-day operational decision-making is delegated to the Programs Director, who, under the supervision of an Executive Committee, runs the organization. The Programs Director together with the Secretariat manages the technical, administrative and financial functions, as well as Programs to support members in their adoption of the personalized Medicine best practices and framework.



Governance activities are not compensated to avoid conflicts of interest. However, operational contributions, such as expert consulting on the actual delivery of certain activities, may be compensated.



# Membership

We welcome membership from institutions, organizations and enterprises that are committed to creating conditions for better access to personalized medicine and engaging with commitment, passion and expertise to generate better patient and health system outcomes. To join the Program, organizations submit an application to the Programs Director, who together with the Executive Committee submits a review and recommendation to the Program Board for a vote. The vote can happen digitally.

#### Members:

- 1. follow the principle of partnership, the key commitments and the governance principles of the Program
- 2. have the right to, and are expected to, participate in the Program's working groups and expert committees;
- 3. have the right to access and use the Program's data, tools and services, in line with relevant legislation;
- 4. have the right to be beneficiaries of services provided by the Secretariat and have the opportunity to access certain licenses from the Program (e.g. "labels", certification marks);
- 5. act as Program Ambassadors.

For-profit members are funding members and pay a membership fee. These members are also required to sign a specific bilateral contract with The Synergist. During the initial incubation phase, seed funding support can also take the form of sponsorship of the Program.

Not-for-profit members are not required to pay a membership fee, and are required to sign a Memorandum of Understanding with The Synergist.

# The Board, Executive Committee and Program's Community

Positions on the Board and Executive Committee are nominative and based on the merits and active participation in the Program's work, as well as proven application of the Program's principles.

The Board consists of up to 18 seats and together with the 3-seat Executive team they form the strategic decision-making body of the Program. According to the principles of collaborative leadership explained under "Key Principles" above, the Program's Board members are elected foremost to act as trustees of the Program ahead of their role as representatives of their respective organizations.

Individuals serving on the Board and Executive Committee shall have strong experience and expertise in the PM area as well as commitment to collaborate and build conditions for better access to PM. This translates into collaborative leadership that respects the principle of non-competitiveness and valuing every individual's expertise and background.

Each member organization is part of the Program's Community.

#### **Board**

#### (1) Composition of the Board

The number of Board members shall always be a multiple of two and may be fixed at any annual Board meeting by a simple two-thirds majority vote. Unless and until otherwise so fixed, the number shall be a **maximum** of 18 (21 including the Executive Committee).

The Board shall be composed according to the following principles:

- minimum 40% of representatives from the patient community;
- maximum 40% of representatives from the pharmaceutical/life sciences industry.
- a minimum /maximum % requirement may be added for other stakeholder types to reinforce the multi-stakeholder approach



• aiming for a balanced representation in gender

Independent Counselors or Honorary Members can be nominated by the current Board, Executive Committee, or Program members entitled to vote and shall be chosen from outside the membership because of their acknowledged capacity to foster the functioning of the governing body, to assist the Board and Leadership in resource development, and to bring to the Board knowledge and diversity that might not otherwise be available from the current Board members. The rules regarding Role and Terms for Independent Counselors and Honorary members shall be the same as those described for other Board members, except for those regarding voting rights. Independent Counselors and Honorary Members shall have no voting rights in the Program's matters.

#### (2) Eligibility and application to the Board

Members apply to the Board through an expression of interest to the Programs Director and the Executive Committee who will assess the eligibility based on the criteria below.

Individuals are eligible for the Board upon fulfillment of the following criteria.

- The individual is an employee of one of the Program's member organizations that has a signed commitment to the Program for at least 1 year for the first exercise (2020), and every 3 years thereafter.
- The Member organization/ individual has proven active commitment, capability to engage and influence a large group of stakeholders inside and outside one's organization and added value to the Program, based on their actual or promised participation in the Program's activities.

Founding Members must fulfill the criteria above along with their mandate to remain nominated.

#### (3) Role of Board members

The Board's role is to set the strategic direction of the Program with input from the Executive team, including defining the vision, mission and the long and medium term objectives of the program, while respecting internal principles and rules.

#### Expectations of the Board

Board members are expected to:

- Be accountable for actively participating in the governance of the organization using their best judgment
- 2. Put the collective needs of the Program first, before that of the individual's or organization's interests
- 3. Remain true to the shared goal and in compliance with all local, national or international regulatory and reporting requirements

In addition, the Board's role is:

- To give a clear mandate to the Executive Committee and to the Secretariat to act on a day-to-day basis, according to the annual work plan;
- To represent the collective interests of Members;
- To understand the changing needs of stakeholders and to help the Program navigate changes in its external environment:
- To foster and nurture partnerships with sister initiatives in the PM space;
- To protect assets and provide financial oversight, supporting in fundraising to ensure sufficient resources (human & financial) to deliver on Program objectives;
- To measure the quality and impact of programs and initiatives, and to identify standards by which to monitor the organization's performance;
- To help cultivate diverse Member (and Board) candidates to ensure that the Board has the ideal mix of perspectives it needs for the program's mission and work;



- To self evaluate the performance of the Board itself;
- To oversee the Executive Committee and the Secretariat's operations, granting them discharge based on the annual work plan and the approval of the annual report and budget.

Board members may be invited to undertake specific tasks or responsibilities, such as acting as a specific liaison between a Working Group and the Board. The role of the Board member is voluntary and is not compensated for.

#### (4) Term, election and rotation of the Board

• The individual is recommended by the Executive Committee. All recommendations are validated for the election by the current Board.

The Executive Committee organizes and monitors the election process.

Any Board or member organization may nominate an individual to serve on the Board. The Executive Committee will review the nominations and present a slate of candidates to the Board for approval. Board members may serve a maximum of two consecutive 3-year terms not including time served when appointed to fill a vacancy in an unexpired term. A Board member who has served two consecutive 3-year terms may serve 2 new consecutive terms after at least one year of absence from the Board.

Any Board member serving on the Executive Committee while their second 3-year Board term expires may continue to serve on the Board until the expiration of their term on the Executive Committee. To maintain the staggered Board term limits, the remainder of the unexpired term shall be filled by a new Board member eligible to serve two consecutive 3-year terms on the Board.

#### (5) Meetings

The Board meets at least twice a year, of which a minimum of one should be a face-to-face meeting.

#### (6) Decision-making process and Quorum

The Board reviews the Program's achievements, work in progress and reporting on a regular 6-month basis and monitors compliance with the project's objectives. Upon receiving the Executive Committee's proposal, the Board revalidates the program's scope and/or organization and rules.

The Board makes decisions through a voting process with a quorum of 7 members, by a simple majority. In case there is no simple majority (50/50), the Executive Committee will take the final decision.

#### (7) Resignation, removal and change in affiliation

Any Board member may at any time resign by a written notice to the Executive Committee and the Executive Director. Any Board member may be removed by the Board together with the Executive Committee, provided that there is a quorum of not less than a majority of the entire Board present at the meeting at which such action is taken and at least two-thirds of those voting endorse removal. Such causes may include, but are not restricted to, absence from three (3) successive meetings of the Board, prolonged incapacity due to illness or injury, conviction of a crime involving moral turpitude, failure to maintain good standing of one's organization as a Program member except where Independent Counselors are drawn from outside membership, neglect or default of assigned and accepted responsibilities, conflict of interest or actions counter to the purposes and policies of the Program.

In case of a Board member changing professional affiliation, or a member organization ending Program membership, her/his Board membership automatically ends either directly or no later than the end of the ongoing year. All membership obligations remain unchanged with the member organization.

#### (8) Conflict of interest

Members of the Board shall scrupulously avoid any conflict between their respective individual interests and the interests of the Program in any and all actions taken by them on behalf of the Program. Any possible conflict of interest on the part of such person or persons shall be disclosed in full detail to the Board and Executive Committee as detailed in the Conflict of Interest policy and such person or persons shall abstain from voting. In addition, such interested Board members must be absent during the Board's vote on the decisions in question. The disclosure as well as the Board member's abstention from voting



shall be made a matter of record within the minutes of the appropriate meeting. Conflict of Interest policy and disclosure form in Annex 4.

#### **Executive Committee**

The Executive Committee has 3 members who are recognized experts and may be external to the Program (i.e. not Program Members). The longest serving Executive Committee member shall act as the Chair of both the Executive Committee as well as the Board.

#### (1) Composition of Executive Committee

The Executive Committee shall be composed according to the following principles:

- The Executive team should aim for members from different stakeholder categories, with a maximum of two members from the same stakeholder category, except for industry which is limited to one.
- In total, at least one member shall be representative of the patient community and one from the pharmaceutical industry.
- As a guiding principle, a good balance of, firstly, international organization leadership and personalized medicine expertise and, secondly, geographic representation should be ensured in the Executive Committee.
- Aiming for a balanced representation in gender, with at least one woman represented on the Executive Committee.

# (2) Eligibility and application to become a member of the Executive Committee

Any Board member may nominate an individual to serve on the Executive Committee. The Executive Committee will review the nominations and present a recommendation to the Board for approval. The approval shall be based on the respect of the guiding principles of the Program governance (notably the duty of loyalty to the Program) and in the composition of the Executive Committee. Approval will also be based on the evaluation of the individual's experience in managing a large group of members or stakeholders and their ability to make clear decisions that support the overall objective of the Program.

#### (3) Role of the Executive Committee member

The Executive Committee is responsible for the supervision of the Programs Director and the day to day strategic management of the project. With their knowledge and know-how the Executive Committee provides valuable support for the Executive Director in the day-to-day operations and decision-making.

The role of the Executive Committee member is voluntary and is not compensated for.

#### (4) Term, election and rotation of the Executive Committee

Every year, at least one member of the Executive Committee will rotate off the Team. The first Executive Committee member rotating off shall serve a final 3-year term on the Board, the second Executive Committee member rotating off shall serve a final 2-year term on the Board and the third Executive Committee member rotating off the Board shall serve a final 1-year term on the Board.

#### (5) Meetings

The Executive Committee meets as often as needed to keep the Program's operations agile and efficient.

#### (6) Decision-making process and Quorum

Decisions are made by a simple majority of the Executive Committee members. If any situations arise that have not been foreseen in this document, the Executive Committee will take the most appropriate decision and notify the Program Board.

#### (7) Resignation and removal

The same rules regarding resignation and removal as in the Program Board chapter apply here. In the unlikely event that the Executive Committee as a whole is contravening the guiding principles, the Board may vote to remove the entire Executive Committee, provided that there is a quorum of not less than a



majority of the entire Board present at the meeting at which such action is taken and at least two-thirds of those voting endorse removal.

#### (8) Conflicts of interest

The same rules regarding conflicts of interest as in the Program Board chapter apply here1.

#### **Program's Community of Practice**

The Program's Community forms a fluid ecosystem of stakeholders that actively contribute to shaping, disseminating and synergizing the Program's activities and outputs. They may contribute by participating in working groups, roundtables, consultations and requests for feedback. Community members support each other's efforts to accelerate collective impact. Each Member organization is part of the Program's Community. The Program's Community is also open to external stakeholders and provides a collaborative environment to organizations that cannot join the Program's official membership for structural and/or governance reasons.

#### **Strategic Advisory Board**

A Strategic Advisory Board (SAB) may be created. The purpose of the SAB will be to provide input into the mid-long term strategic direction of the Program. Each member organization will have a seat on the SAB and is thus a way for all members, not only the Board members, to provide input. The SAB will be activated by a decision by the Board if it is judged that the Program's increasing size warrants a SAB to better engage with members.

#### **Ethics Committee**

An Ethics Committee may be created. The Ethics Committee will be activated by a decision by the Board based on the evolving needs of the Program.

# **Scientific Advisory Committee**

A Scientific Advisory Committee may be created. The Scientific Advisory Committee will be activated by a decision by the Board based on the evolving needs of the Program.

# **The Synergist**

The Synergist has been appointed to act as the trustee and to take care of the operations of the Program.

# Role/mandate

The Synergist has multiple mandates encompassing the following items:

#### **Secretariat**

The Synergist takes care of all administrative duties linked to the Program management and membership, including organizing and facilitating the meetings, preparing summary reports, etc.

#### Host and facilitator

The Synergist acts as a neutral host of the Program. The Program will not be incorporated at any stage, therefore The Synergist will host the project and will act as a proxy holder on behalf of the Program, under the Executive Committee's guidance.

#### **Project Management**

The Synergist organizes and makes its teams available to perform the necessary duties to achieve

<sup>&</sup>lt;sup>1</sup> See Conflict of Interest policy in Annex 4



the Program's goals as set by the Board and the Executive Committee.

# **Funding**

Funding for the Program shall come from several complementary sources described hereafter. The funding is managed through the Synergist as the Program is not a legal entity.

Core funding of the project shall be provided for by industry ("Industry") and other for-profit members.

The Board approved<sup>2</sup> unanimously to proceed with the **Tiered fee membership (based on annual turnover)** in combination with the option to contribute to **special projects**.

Members commit to a 3-year membership and an annual membership fee shall be charged as follows for Industry or for-profit members:

	pany Yearly tu	Fee (EUR)		
Tier 1		> 10 billions	100k	
Full members	Tier 2	1 b. < x < 10 b.	<b>75</b> k	
	Tier 3	< 1 b.	50k	
Associate Members (not eligible for Board, ExCo or SAB)*		-	Lower amounts	

In the incubation phase, funding may be provided via sponsorship of the Program.

# **Project-specific funding**

Additional funding for specific projects or member specific products and services is possible.

# **Alternate funding**

The Program might raise alternate funding including (but not restricted to):

- Foundations
- Public Institutions
- Private donors
- For-profit funding for specific projects

Any exception to the above funding principles has to be approved by the Executive Committee and the Board needs to be informed.

<sup>&</sup>lt;sup>2</sup> During the Board Meeting on December 15th, 2020



## **Conflict resolution**

The governance has been designed to avoid conflicts. Should this occur, the Executive Committee will take the appropriate decision and inform the Program Board.

# **Liability of members**

The Program is not a legal entity, therefore it is not liable per se. All members will be liable for their own actions and decisions.

It is therefore not expected that any member would increase or modify its usual liability because of its commitment to the Program.

# Intellectual property

A significant part of this Program's expected outcome will be intellectual property (IP). As per the principles of collaborative leadership, tools and information produced by the Program should be open and accessible to anyone. Accordingly, everything produced by the Program is managed by a Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International (CC BY-NC-SA 4.0) license.

#### What are Members allowed to do with the Program material?

By licensing our work with the CC BY-NC-SA 4.0 license it means that you may:

- Share copy and redistribute the material in any medium or format
- Adapt remix, transform, and build upon the material

It does however mean that when you use it you must:

- <u>give appropriate credit</u> (see example statements below), you must provide the name of the creator and attribution parties, a copyright notice, a license notice, a disclaimer notice, and a link to the material
- provide a link to the original CC BY-NC-SA 4.0 license –https://creativecommons.org/licenses/by-nc-sa/4.0/
- indicate if you modified the material and retain an indication of previous modifications
- If you remix, transform, or build upon the material, you must distribute your contributions under the same license as the original (CC BY-NC-SA 4.0). You may not apply legal terms or technological measures that legally restrict others from doing anything the license permits.

You can do this in any reasonable manner, but not in any way that suggests that the Program endorses you or your use.

#### You may not:

Use the licensed material for commercial purposes. Commercial use means primarily intended for
or directed towards commercial advantage, payment or monetary compensation, which would
be a violation of the license. (Three examples of commercial and non-commercial use are given
below). Any requests to use the licensed material for commercial purposes must be addressed
first with The Synergist.

The above is an easy to read summary of the license but does not substitute the legal text which is available to read and for download at <a href="https://creativecommons.org/licenses/by-nc-sa/4.0/legalcode">https://creativecommons.org/licenses/by-nc-sa/4.0/legalcode</a>

The license may not give you all of the permissions necessary for your intended use. For example, other rights such as publicity, privacy, or moral rights may limit how you use the material. You do not have to comply with the license for elements of the material in the public domain or where your use is permitted by an applicable exception or limitation.



#### How to give appropriate credit Example statements

Appropriate credit in the case of using Program content where you have not changed anything:

"Deliverable name" by Program is licensed under CC BY-NC-SA 4.0

Appropriate credit in the case of using Program content and you have changed something:

"My work name" is a derivative of "Deliverable name" by Program used under <u>CC BY-NC-SA 4.0.</u> "My work name" is licensed under <u>CC BY-NC-SA 4.0.</u> by M. X

Non-commercial and commercial use

Creative Commons defines non-commercial use as – "not primarily intended for or directed towards commercial advantage or monetary compensation. For purposes of this Public License, the exchange of the Licensed Material for other material subject to Copyright and Similar Rights by digital file-sharing or similar means is Non-Commercial provided there is no payment of monetary compensation in connection with the exchange."

# Withdrawal or exclusion of members

Members can decide to withdraw from the project. Their specific obligations in such a situation shall be provided for by the bilateral contractual arrangements.

The withdrawing member should honor outstanding commitments (activities/financial) prior to withdrawal.

The Executive Committee may decide to exclude members for serious breaches to the Program's philosophy or to the Governance. The Board will endorse any member exclusion.

# Closure - end of the Program

The Board may decide to put an end to the Program either because all expected outcomes of the project have been delivered or because serious and objective forecasts show that it will not be possible to deliver these outcomes.

This decision shall be endorsed by a qualified majority vote from the Members. If a decision to stop the project is made by the Board, the program's IP and assets can be used by The Synergist to pursue a similar or related mission.



# **Annex 1 - About The Synergist**

The Synergist is a not-for-profit organization that offers a symbolic and material neutral platform where all stakeholders can collaborate in a non-competitive environment, understanding that they join forces on an issue which is beyond a single organization's agenda.

The Synergist believes that creating shared value and addressing the common causes that link key concerns is what leads to greater results. The Synergist partners with corporations, influencers, experts, academics, individuals, medical professionals, patients, and NGOs, among others, who share the same philosophy.

The Synergist acts as an incubator and leads various projects including implementation of strategy, management, communication, technical development and fundraising. To learn more about our activities, please refer to www.TheSynergist.org

#### What drives us

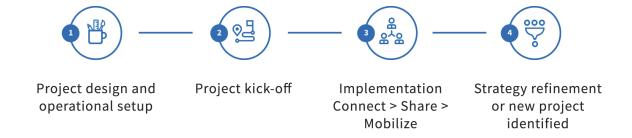
Like many, we're driven by a desire to make the world a better place. Some of our Programs stem from very personal and emotional experiences faced by members of our team.

Most pertinently, we strongly believe our approach can drive success. Collectively, we have decades of experience in business and government, and have all been left frustrated by the deep-seated silos inherent in organizations dealing with challenges that require collaboration.

The Synergist seeks to remedy this. We're small and nimble enough to be silo-proof, and provide a platform for people, and organizations large and small, to work together.

#### How we work

Our Programs vary greatly, but we always follow the same simple approach.



#### How we are structured

Our main role is to act as an incubator: we identify the right people and organizations for each Program, bring them together, and provide overall strategic direction and coordination. In parallel, we manage fundraising, communications and technical development.

Each Program has a Program Task Force, including a Program Director, necessary support staff and a dedicated Board. The latter is made up of individuals with specific expertise or interest on the specific issue covered by the Program, and helps to develop each Program's strategy and provides expert input at all stages of execution.



# **Annex 2 - The Synergist Travel & Expenses Policy**

This policy is, to a large extent, inspired by the <u>World Health organization's staff regulations and staff rules</u>, version February 2018.

Within this document, the following terms shall be understood as follows:

- The organization: The Synergist ASBL and any of the hosted programs
- Recipients: Any individual entitled to expenses reimbursement and / or travel reimbursement by The Synergist. Such individuals are employees of The Synergist, members of the Executive Committee and members of the Board from not-for-profit organizations. All other members shall not be considered as Recipients. Delegates or representatives attending on behalf of the Executive Committee or the Board members are not automatically considered as Recipients and therefore will be considered on a case-by-case basis.

Subject to conditions and definitions below, the organization shall pay the travel expenses of Recipients.

#### Travel and transportation

The organization shall pay the reasonable travel expenses of Recipients as follows:

- Reasonable travel expenses shall be paid by the organization only if the travel purpose is linked to one of the Programs or projects hosted by the organization. Prior approval of the organization is requested, taking into account that travel expenses related to Executive Committee and Board Members (from not-for-profit member organizations) whose attendance to meetings is requested will always be considered approved. The cost to the organization for travel covered by this rule shall not in any case exceed that of travel from the Recipient's recognized place of residence to the meeting place.
- For total expenses equal to 500.00€ or more for one meeting advance approval is requested by the organization.

#### Travel per diem & expense reimbursements

If a Recipient is paid a travel per diem during any period of authorized travel, the rates of travel per diem and the conditions under which they shall be payable to Recipients shall be established in accordance with the rules published by the Belgian Fiscal Administration. The amount of the per diem is considered to represent an average payment in lieu of reimbursement of a portion of the actual incidental expenses occasioned by travel status.

The Recipient may claim incidental expenses occasioned by travel up to the same amount as a per diem payment per day, through the organization's official expense claim form and attaching the relevant receipts. Please check with the organization for details of per diem amounts in different countries if needed.

#### Route and mode of travel

All travel at the organization's expense shall be by a route and mode of transportation determined by the organization, provided that the Recipient may be permitted to choose a different route or mode of transport on condition that any extra costs are at their charge, and that per diem calculations shall be made on the basis of the route and mode of transport designated by the organization.

#### Failure to exercise entitlement

In no case shall a Recipient be given any cash payment in lieu of exercising any entitlement under this rule. Any entitlement which is not exercised within one month of the entitlement date shall be forfeited except upon the express approval by the organization's management.



# **Annex 3 - Board Members & Executive Committee**

# Board Members & Executive Committee 2021

Board 2021							
1	Sarah Jennifer Knott Foundation	Patient organization					
2	Canadian Organization of Rare Disorders	Patient organization					
3	KUZ - Coalition of Association in Healthcare (Croatia)	Patient organization					
4	CML Advocates Network	Patient organization					
5	Lungevity	Patient organization					
6	Genome Creative	Individual Patient					
7	Roche	Industry					
8	Janssen	Industry					
9	Lilly	Industry					
10	Illumina	Industry					
11	Bayer	Industry					
12	Dr. Benedikt Westphalen (Comprehensive Cancer Center Munich)	Other					
13	Sant Joan de Déu Research Foundation	Other					

Program Executive Committee 2021				
1	Denis Costello	CML Advocates Network		
2	Andrea Ferris	Lungevity		
3	Shirlene Badger	Illumina		



# **Annex 4 - Conflict of Interest policy**

#### Introduction and purpose

Individuals serving on the Program's Board and Executive Committee or Individual Counselors have experience and knowledge about the medicines R&D and the willingness to drive personalized Medicine forward and collaborate to make it systematic. This experience and knowledge come from long-term and in-depth involvement with all relevant stakeholders at both a national and international level. As a consequence of that experience, it is inevitable that these individuals will have a number of legitimate ongoing interests with different public (both government and non-government) and private (e.g. pharmaceutical companies, medical device companies, healthcare providers etc.) organizations. The purpose of the Disclosure of Conflict of Interests is to protect the individual and the Program from any suggestion or perception of impropriety.

Conflicts of interest may arise when a person's personal, business, occupational or professional interests' or affiliations may conflict with the discussions held or decisions made in the Program. This may be because they serve on multiple boards of potentially competing NGOs, may have commercial or regulatory interests, or whatever.

The Program does not want to limit or influence in any way Board members' or Executive Committee's involvement with other organizations - the disclosure is to provide transparency and help understand whether a potential conflict of interest exists.

In the light of the above, we are asking all Board members and the Executive Committee to make a disclosure of their interests on an annual basis.

Please identify what these interests are by returning the form on the next page. This will be provided to all Executive Committee members but not made available publicly.

Please complete and return this Disclosure of Conflict of Interests form to the Programs Director [office@thesynergist.org] latest during the first 3 months of the beginning of your term and annually thereof.

#### **Process of determination**

#### **Determinations of Conflict of Interest**

A Board or Executive Committee Member or Individual Counselor who has declared or has been found to have a conflict of interest shall refrain from participating in the Board or committee meeting while the determination of a conflict of interest is discussed and voted upon, unless for special reasons the Board requests information or interpretation from the person or persons involved or determines that the interested person may remain in the room. He or she shall not vote on the matter in question and shall not be present at the time of the vote unless the Chair and/or Board determines that the conflict is insignificant or immaterial to the issue at hand. More detailed procedures of determination and addressing conflicts of interest are laid out in the *Conflict of Interest procedures*-document<sup>3</sup>.

<sup>&</sup>lt;sup>3</sup> https://docs.google.com/document/d/1vneU7OxRoSC29GybnmTPhNK3fyQvM6p2dJU\_LHj0hvg/edit?usp=sharing



# Disclosure of Conflict of Interest

Your Name:	
Position:	
organization(s):	
Email:	
Date:	
knowledge, th <u>Independent (</u>	y involvement in the abovementioned organization(s) I declare that, to the best of my ne only interests that are relevant to my role on the <u>Board/ Executive Committee / as Counselor in companies and organizations are those listed below.</u> If the companies and organizations are those listed below.  If the companies are those listed below.
Employment	
	vith a pharmaceutical company means any form of occupation, part-time or full-time, paid
•	the company. This includes also companies relating to medicinal products, e.g. contract
research organ	nizations (CROs), but not academic institutions.
Enter text belo	w. If nothing to declare, add "nothing to declare".
Consultancy a	and/ or Strategic advice
Consultancy i	means provision of advice to a pharma company, public institution or healthcare regardless of contractual arrangements or any form of remuneration or provision of
board or Board activities of a	sory role means participation (with a right to vote on/influence the outputs) in an advisory d with the role of providing advice, expressing opinions on the (future) strategy, direction or pharma company, public institution or healthcare organization, regardless of contractual or any form of remuneration or provision of pro-bono services.
Enter text belo	w. If nothing to declare, add "nothing to declare".

#### **Financial interests**

Current or potential ownership, investment interest or holding of stocks and shares, stock options, equities, bonds and or partnership interest in the capital of any entity with which the Program has or is negotiating a transaction or arrangement (with the exclusion of an investment fund, pension fund and/or similar arrangements).

Current intellectual property rights including patents, trademarks, know-how and/or copyrights relating to medicinal products or healthcare service owned by you or of which you are directly a beneficiary.

Current or potential compensation arrangement (including direct and indirect remuneration as well as gifts or favors that are substantial in nature) with the Program or with any entity or individual with which the Program has or is negotiating a transaction or arrangement



Current position	on as an	officer of	or board	member,	employee,	or former	employee	of any	entity	with \	which
the Program h	as or is	negotiat	ing a trai	nsaction o	r arrangem	nent					

Enter text below. If nothing to declare, add "nothing to declare".	

#### Grant, funding to organization(s) and institution(s)

Current grants or other funding (other than compensation for services provided e.g. for consultancy) received from a pharmaceutical company, healthcare organization or governmental institution by an organization/institution to which you belong, or for which you perform any kind of activity, and which is used to support any of your activities whether or not they are related to your (patient advocacy) work. Any other funding received from a pharmaceutical company by an organization/institution to which you belong, or for which you perform any kind of activity, do not need to be declared.

Enter text below. If nothing to declare, add "nothing to declare".

#### Any other interests or facts

Date and signature:

Provide information on involvement with additional organizations, institutions, initiatives or projects that may create a potential conflict of interest, e.g.:

- Academic and/or publicly funded research initiatives in healthcare
- Officer, director, trustee, employee, or consultant to any other professional society, research organization, non-profit organization or corporation in healthcare, which may be funded in full or in part from unrestricted grants from pharmaceutical companies or governmental bodies, or may have potential conflicts of interest with the Program
- Employment, consultancy, strategic advisory role and financial interests of first-line family members (i.e. spouse or partner, children and parents)

Enter text below. If nothing to declare, add "nothing to declare".

Should there be any changes to the above due to the fact the promptly notify the Program and submit an updated Disclosu changes.	,