



# Trustee Handbook

## Welcome to the Myrovlytis Trust

The Myrovlytis Trust promotes research into rare genetic disorders such as Birt-Hogg-Dubé syndrome and rare cancers such as Osteosarcoma and has funded more than £6 million in research grants to laboratories around the world.

We are in a period of reinvigorating the charity, our strategic goals and mission, and we are delighted to welcome new board members to help us realise our vision as we embark upon a new era of funding research and providing advocacy. This is an exciting time to be joining a small but agile charity with big plans as we expand our remit in the world of rare diseases.

This handbook sets out the purpose, responsibilities and roles expected of all Myrovlytis Trust Trustees. It has been designed to provide you with an understanding of how we operate as an organisation and what is expected from you in your role as a trustee.

We value you as a trustee and are grateful for the continued support and commitment you bring to the Myrovlytis Trust.

We hope you find all the information and resources you need to support you in your role as a trustee within this handbook. If you need any further information or help in any way, please contact me at [anna@myrovlytistrust.org](mailto:anna@myrovlytistrust.org)

**Anna Webb**  
Charity Director

## About the Myrovlytis Trust

The Myrovlytis Trust is a charity founded in 2007 to promote research into rare diseases, and advance education of the public in medical and molecular genetics.

More than **7000** rare diseases have been described, affecting **300 million** people globally. On average, it takes over **4 years** for an individual to receive a diagnosis, and even then, only **400** of these diseases have an approved treatment.

We **passionately** believe that no one should be disadvantaged because they have a rare disease.

By providing information and support to patients, raising awareness among clinicians and the public and strategically funding research, the Myrovlytis Trust aims to **transform** the outlook for rare diseases.

With an initial focus on two conditions, **Birt-Hogg-Dubé Syndrome (BHD)** and **Osteosarcoma**, we fund research directed towards new treatments.

We want to ensure that patients gain **access** to the same state-of-the-art technologies, breakthroughs, and therapies as those with more common disease.

The Trust's principal objectives are to carry out high quality translational research into rare diseases, specifically Birt-Hogg-Dubé Syndrome (a rare genetic disorder) and Osteosarcoma (a rare cancer), to provide support, advocacy, education for patient groups and to raise awareness among the public and clinicians.

Myrovlytis Trust UK Charity Commission number 1122073.

## Delivering the Myrovlytis Trust's Mission and Goals

### Through Education and Advocacy

Having a rare disease can be an isolating and anxiety-inducing experience. The journey to a diagnosis can be long and winding, and with a diagnosis comes new questions. It can be hard to find a doctor who understands the condition, and patients often become their own best advocate.

We strongly believe that by forming communities and connecting patients, researchers and clinicians, we can drive innovations in research and support and empower patients.

Through the **BHD Foundation** we have established a template for support, research, and innovation in the rare disease field, which we intend to replicate in our work on osteosarcoma and eventually expand to a range of conditions.

We believe that by establishing a comprehensive information source, regular meetings, clearly explaining the science and involving patient groups at every stage we will work more effectively to improve the outlook for patients.

### Through Research

Our research strategy is guided by a simple overarching framework; to bring together researchers, clinicians and patients in collaborative multi-disciplinary projects which drive forward new technologies and potential therapies. We have a particular interest in immunotherapies and new routes to treatment.

The following principles guide the Myrovlytis Trust's research strategy:

1. Relevance to the treatment or cure of rare diseases.
2. Potential to improve the prognosis and quality of life of people affected by rare diseases.
3. Evidence that funding cannot be suitably obtained elsewhere.
4. Originality and excellence of science.
5. Dissemination of research to the scientific community through publication of results, and to the wider population through public engagement in line with the aims of the Myrovlytis Trust to bring clinicians, researchers and patients together to advance the field.
6. Potential of new advances in technologies and tools in the clinic to be applicable to other related rare diseases.

## Myrovlytis Trust Staff

Trustees elect to delegate day to day running of the Myrovlytis Trust to the Charity Director. The Charity Director reports directly to the Board of Trustees and is supported by a staff team as below.

The day-to-day activities of the Myrovlytis Trust are coordinated by a team of 4, all recruited in 2021 to push forward our aims in this new era for the Trust.



**Charity Director: Anna Webb**

After completing a PhD at the MRC Human Genetics Unit (now IGGM) in Edinburgh, Anna undertook postdoctoral research at UCL before moving to scientific publishing (Acquisitions Editor then Senior Editor of a medical genomics journal). She also gained several years of conference and events experience before joining the Myrovlytis Trust.

Email: [anna@myrovlytistrust.org](mailto:anna@myrovlytistrust.org)



**Charity Officer: Jazzmin Huber**

Following a degree in Cancer Biology and Immunology at the University of Bristol and a Medical degree at the University of Birmingham, Jazzmin worked as a Doctor for the NHS, before joining the Myrovlytis Trust as a Charity Officer in February 2021.

Email: [jazzmin@myrovlytistrust.org](mailto:jazzmin@myrovlytistrust.org)



**Charity Officer: Katie Nightingale**

Katie completed her PhD at the Roslin Institute in Edinburgh before moving to the University of Cambridge to undertake her postdoctoral work. She joined the Myrovlytis Trust as a charity officer in May 2021.

Email: [katien@myrovlytistrust.org](mailto:katien@myrovlytistrust.org)



**Office Manager: Katie Honeywood**

Katie has over 20 years' experience within a variety of administrative roles and has developed extensive experience in office management. Katie completed her ILM Level 5 in April 2021. She joined the Myrovlytis Trust as office manager in June 2021.

Email: [katieh@myrovlytistrust.org](mailto:katieh@myrovlytistrust.org)

## Myrovlytis Trust Board of Trustees

Dimitris Padagogopoulos  
(Chair)

Vinay Paladugala

Morris Saleh

## Myrovlytis Trust Science Advisory Board



**Professor Eamonn Maher**  
MD FRCP FMedSci,  
Professor of Medical  
Genetics and Genomic  
Medicine, University of  
Cambridge



**Dr Laura Schmidt**  
PhD, Principal Scientist  
at the National Cancer  
Institute, NIH, USA



**Professor Ann Nordgren**  
Ann Nordgren is Adjunct  
Professor of Clinical  
Genetics at Karolinska  
Institutet and Senior  
Consultant at the  
Department of Clinical  
genetics, Karolinska  
University Hospital



**Professor Manuel Ramirez**  
Manuel Ramirez is  
Head of the Advanced  
Therapy Unit  
at Hospital  
Universitario Niño  
Jesús, Madrid



**Professor Andrew Tee**  
PhD, Research Lecturer  
at the Institute of  
Medical  
Genetics of Cardiff  
University School of  
Medicine, UK  
and AICR fellow



**Professor Alejandro Sweet-Cordero**  
Alejandro Sweet-  
Cordero, Leader of the  
Molecular Oncology  
Initiative (MOI) at  
UCSF



**Professor Arnim Pause**  
PhD, Associate Professor  
in the Department of  
Biochemistry and Canada  
Research Chair in  
Molecular  
Oncology at McGill  
University, Canada



**Professor William Newman**  
William Newman is a  
consultant Clinical  
Geneticist in  
Manchester and the  
Clinical Director of  
the NW Genomic  
Medicine Service  
Alliance (GMSA)



**Dr Dimitrios Iliopoulos**  
Dr. Dimitrios Iliopoulos is  
co-founder & Chairman  
of Attica Sciences Ltd



**Professor Daniel Gale**  
Daniel Gale is St  
Peter's Chair of  
Nephrology  
at University College  
London



**Dr Tian Zhang**  
Tian Zhang, Associate  
Professor within the  
Division of Medical  
Oncology  
and Department of  
Medicine at Duke

## Myrovlytis Trust's Strategic Direction

### A) Articles of Association

The Articles of Association are the legal governing documents for the Myrovlytis Trust. They create a company and delegate the management of that company to the Directors (in our case Trustees). The Articles of Association form the basis of the company's constitution. They form the basis of Myrovlytis Trust's mission, values, and aims, all of which are detailed and referred to in the following plans.

### B) Business Planning

The Myrovlytis Trust's Business Plan runs from **2021- 2024**. This plan helps to ensure all activities and efforts are focussed on the Myrovlytis Trust's overall aims, objectives, and priorities during this time. The Board is responsible for the formation of the Strategic Plan alongside the Charity Director and other staff members, where applicable.

### C) Operational Planning

Operational Project Action Plans are created annually, which detail the actions required to ensure Myrovlytis Trust's aims and objectives are achieved.

Myrovlytis Trust are bound by legal obligations to prepare Annual Accounts which have been independently audited by external accountants (BWP Inspire Ltd). These accounts are presented to and approved by the trustees annually and submitted to the Charity Commission and Companies House.

The Board are responsible for the formulation, monitoring and implementation of such plans and accounts at a strategic level. The Board will only provide operational support as required, via the use of subgroups or committees, or within exceptional circumstances.

The Board will ensure that staff have the necessary skills, resources, and support to undertake the activities described in these plans.

### D) Reserves Policy

The Myrovlytis Trust aims to follow a reserves policy, whereby a set period's (ideally 6-9 months') operational costs are maintained.

## Myrovlytis Trust's Board

### 1. Board Structure

It is important that the Myrovlytis Trust's Board represents a mix of well skilled, committed individuals. It is the Board's responsibility to ensure there is always enough trustees to govern effectively. This needs to be balanced against keeping to the maximum number of trustees (8) at any given time, depending on the skills and experience required for the strategic development of the Myrovlytis Trust Board. The Trust requires a **51%** attendance to meet the meeting quorum.

### 2. Voting rights

Each member of the board has one vote and can vote at meetings or by proxy.

Decisions can only be carried if it contains a majority of the Trustee vote.

### 3. Roles within the Board

In addition to the general duties and responsibilities listed in this document, some Trustees will be given additional responsibilities via the roles described below.

#### 1) Chair

It is the Chair's responsibility to lead the Board.

The Chair acts as a supervisory role to the Myrovlytis Trust's Charity Director and has the responsibility of acting as a figurehead for the Myrovlytis Trust.

#### 2) Vice-Chair

The Vice-Chair can carry out the Chair's duties in their absence (or should they not be able to contribute due to a conflict of interest) with the acknowledgement of the Board as being capable of doing so. The Vice- Chair also aids the Chair and support them in their role.

This includes managing Board meetings via a comprehensive agenda and prior planning. The Vice-Chair should ensure all Trustees can take part equally, as well as continually facilitate discussion, summarise decisions and present information clearly and concisely, to ensure the Board always makes effective decisions.

It is the Vice-Chair's responsibility to check all actionable items resulting from Board meetings have been completed, as well as monitoring the governance best practice with support from the Clerk.

The Vice-Chair is responsible for the delegation of actionable items to appropriate Trustees (or staff) and is responsible for overall Board 'health' and standards. This includes ensuring all Trustees receive adequate inductions and training, so they can effectively fulfil their roles. The Chair continually monitors the level of commitment and attendance of all trustees.

Trustees can raise any concerns or issues regarding the Chair to the Vice- Chair.

### **3) Clerk**

The Clerk will not be a trustee of the Myrovlytis Trust and is in place to provide administrative support and advise to the Chair and Vice-Chair.

Their role is to ensure the Myrovlytis Trust complies with Charity Law, as well as other legal requirements. Responsibilities include ensuring all necessary documentation is sent to Companies House and the Charity Commission within the deadlines set.

The Clerk is responsible for ensuring all Board documentation is always up to date and accessible to all board members.

The Clerk is responsible for compiling board meeting documentation and taking minutes at the set board meetings and any other board events as and when required.

The Clerk acts as the Myrovlytis Trusts point of contact for Freedom of Information requests.

### **4. Tenure and Membership**

To ensure the overall skills and experiences of the collective Trustees remain relevant, appropriate, and effective, Board recruitment and membership renewal should be a process of continual improvement and self-evaluation. Therefore, an annual skills audit is completed to ensure the Myrovlytis Trust remains resilient and able to adapt to the changing external and internal environment within which it operates.

To ensure the time commitment of all Trustees remain fair and achievable, as well as ensuring continual growth and adoption of new skills and experiences is encouraged, a tenure system is in place.

Following the initial period of observation and satisfactory references, potential trustees are invited to join the board for an initial period of three years.

Following this period, tenure may be extended for a further three years (subject to a Trustee meeting vote). Such circumstances will be determined by the current Board needs relative to the skills, experience, and commitment of the Trustee in question, as well as the requirements of the organisation at any given point in time. Should exceptional circumstances dictate, a Trustee may be invited to remain a member of the Board for a further 1 year, dependant on the need at that given point in time and subject to Board approval.

Trustees may resign before their set term ends. Resignation will need to put in writing to the Chair. As a Board, Trustees' have a responsibility to ensure the minimal size for the Trustee Board is maintained. Therefore, the resigning Trustee may be required to continue in their service until a suitable replacement is found.

The Board of Trustees have a right to remove a trustee at any time, provided the correct procedures are followed according to the Companies Act 2006. Such acts may be the result

of a vote of no confidence, or because of circumstances which may damage the charity's reputation.

## Myrovlytis Trust's Board of Trustees Terms of Reference

Key functions and responsibilities

### 1. Being a trustee

To qualify as a charity trustee, you must meet the following criteria as established within the [Charity Governance Code](#)

- You must be 18 years of age to become a trustee.
- You must not act as a trustee if you are disqualified, unless authorised to do so by a waiver from the Charity Commission. The reasons for disqualification include:
  - having an unspent conviction for an offence involving dishonesty or deception (such as fraud)
  - being bankrupt, or entering into a formal arrangement (eg an individual voluntary arrangement) with a creditor
  - removal as a company director or charity trustee because of wrongdoing
- New reasons for disqualification were added on 1 August 2018. These include:
  - being on the sex offenders' register
  - unspent convictions for a wider range of offences including bribery and money laundering
  - disobeying a direction of the Commission.
  - The disqualification rules [guidance](#) explains the changes in more detail.

If any of the current or new disqualification reasons apply to you, you may be able to get your disqualification lifted (or 'waived') by the Commission.

The Commission will carefully consider whether granting a waiver is appropriate, although there are some situations where it has no power to grant a waiver – for example, where a trustee is disqualified as a company director.

All Trustees are expected to view and practice their role on the Board as independent of their personal interests or relationship to the Myrovlytis Trust. They should declare a conflict of interest at a board meeting if an issue arises.

Trustees should not receive any benefit from the charity unless it is properly authorised and is clearly in the charity's interests. This also includes anyone who is financially connected to you, such as a partner, dependent child or business partner. You must declare any benefit to the Boards Chair and Clerk.

As a Trustee, you are expected to behave in a manner that appropriately reflects the Myrovlytis Trust's values.

## 2. Joining the board

Trustees are invited to join the board following completion of the Myrovlytis Trust's application process. This process will give the Myrovlytis Trust the opportunity to assess the skills and qualities required for new Trustees, and to recruit for gaps in the existing group based on the requirements of the annual Board skills audit.

The application will take the form of a written statement and CV, which will be followed by an informal interview with Myrovlytis Trust's Charity Director and Chair.

Appointment as a trustee will be subject to the receipt of satisfactory references.

## 3. Responsibilities

As a trustee, you will fulfil a crucial role in contributing to the Myrovlytis Trust's organisational strength, sustainability, and growth.

It is crucial all Trustees understand how the Myrovlytis Trust works and how your specific skills can support the work we do. Some of these responsibilities include:

- Establishing and overseeing institutional policy and strategic direction, including defining goals, setting targets, and evaluating performance. This includes overseeing the implementation of the Strategic, Business and Operational Plans.
- Ensuring the Myrovlytis Trust acts within charity law, and against all relevant legislation, regulation and meets the requirements of good governance and leadership.
- Monitoring whether activities undertaken comply with the governing purpose, mission, values and aims.
- Monitoring the financial position, ensuring it operates within its means and that there are clear lines of accountability for day-to-day financial management.
- Evaluate the Myrovlytis Trust's effectiveness in accomplishing its mission.
- Evaluating the performance and responsibilities of Myrovlytis Trust's Charity Director.
- Helping to recruit and support new board members.
- Ensuring appropriate procedures and safeguards are in place and take reasonable steps to ensure that these are followed.
- In addition to the above statutory duties, each board member should use any specific skills, knowledge or experience they have to assist the board in reaching sound decisions. This involves:
  - Scrutinising board papers
  - Leading discussions
  - Focusing on key issues
  - Providing guidance on new initiatives

- Other issues in which the board member has special expertise

#### 4. Skills and Qualities Required

- Commitment to the aims, principles, and purpose of the Myrovlytis Trust. This includes willingness and ability to always act in the best interests of the charity.
- Trustees must be willing and able to devote the necessary time and effort to the role of a trustee including time to thoroughly read and scrutinise reports provided to the board and attend required meetings.
- Effective communication skills and willingness to participate actively in discussion.
- Act with integrity and in the Myrovlytis Trust's best interests, avoiding conflicts of interest, and using reasonable skill and care. This may include seeking external professional advice where necessary.
- An ability to work effectively as a member of the team and to take decisions for the good of the Myrovlytis Trust as a whole.
- Be able to offer objective, rational and unbiased guidance always.
- Act as an advocate and ambassador for the Myrovlytis Trust within the organisation and externally through your networks.

#### 5. Knowledge Required

Trustees hold a legal responsibility in their duty to the Myrovlytis Trust. In order to ensure you are able to effectively govern to the required standard and be an effective member of Myrovlytis Trust's Board, it is important you have, or make the necessary steps to achieve the following recommended baseline of knowledge.

Trustees must:

- Fully understand the purpose and aims of the Myrovlytis Trust.
- Have awareness and understanding of the funding structures that affect the Myrovlytis Trust.
- Fully understand the roles and responsibilities of the Board of Directors, including the governance and legal responsibilities carried by Trustees.
- Fully understand the roles and responsibilities of the Myrovlytis Trust's staff
- Have complete awareness of Company Policy Documents.

#### 6. Code of Conduct

The Myrovlytis Trust has a Code of Conduct which is inline with the Charity Governance Code represents a standard of good governance practice to which all charities should aspire.

The Myrovlytis Trust has a Code of Conduct which a trustee will be provided with on commencement of term.

Trustees of the Myrovlytis Trust must abide by the following fundamental values:

1) Selflessness

Trustees should take decisions solely in terms of the interest of the Myrovlytis Trust and not for their own personal gain.

2) Integrity

Trustees must avoid placing themselves under any obligation to people or organisations that might try inappropriately to influence them in their work. They should not act or take decisions to gain financial or other material benefits for themselves, their family, or their friends. They must declare and resolve any interests and relationships.

3) Objectivity

Trustees must act and take decisions impartially, fairly and on merit, using the best evidence and without discrimination or bias.

4) Accountability

Trustees are accountable to the Myrovlytis trust for their decisions and actions and must submit themselves to the scrutiny necessary to ensure this.

5) Openness

Trustees should act and take decisions in an open and transparent manner. Information should not be withheld from the Myrovlytis Trust unless there are clear and lawful reasons for so doing.

6) Honesty

Holders of public office should be truthful.

7) Leadership

Holders of public office should exhibit these principles in their own behaviour. They should actively promote and robustly support the principles and be willing to challenge poor behaviour wherever it occurs.

## 7. Trustee Agreement

All Trustees are expected to:

- Attend all board meetings (planned or called)
- Read and respond to all information, papers or reports provided to the Board within the required timeframes.

## 8. Conflict of Interest

The Myrovlytis Trust asks that all trustees familiarise themselves with and the Conflict of Interest Policy. All trustees are required to complete the Conflict of Interest Disclosure Form. Both the policy and form will be provided to the trustee on commencement of term.

## Myrovlytis Trust Board Administration Information

### 1. General Meetings

The Myrovlytis Trust's Board hold four board meetings each year. As a Trustee, you are expected to attend all meetings. The Chair has the right to ask that a Trustee stand down from the Board if three consecutive meetings are missed without a valid reason.

If a trustee is unable to attend a meeting, they must let the Clerk know with as much notice as possible. This must be done via email, in which case the Clerk will confirm acknowledgement in writing. It is the Trustees responsibility to ensure their non-attendance is acknowledged.

Trustees are required to read all Board papers prior to each meeting and must contribute to the best of their ability and provide input regardless of whether they are able to attend the meeting in person.

All Trustees are entitled to ask for a Board meeting to be called however whether such meeting is held in practice will be at the Chair's discretion, dependant on the requirements and reasons provided.

The Chair reserves the right to call an extraordinary board meeting as and when they should be required. These will only be called during exceptional circumstances that require immediate attention and decisions to be made.

### 2. How do the Board meetings work?

The agenda for each meeting is set by the Vice Chair in conjunction with the Charity Director and supported by the Clerk. The agenda will have clear actionable items and points to discuss. The Vice Chair will invite all Trustees to raise any items or issues to be included in the agenda prior to each meeting.

All board meetings shall not last longer than two and a half hours, including a break if required. Trustees will be informed of the location of each board meeting with as much notice as possible.

Papers will be circulated to all Trustees at least five days before each meeting via email. This is required to ensure all Trustees have enough time to read and understand all items on the agenda and prepare accordingly. It is the responsibility of the Trust to print their own papers should they require hard copies.

There may be some instances where papers are 'held' until full review during the board meeting, however this will be actively avoided where possible.

### 3. Events and networking opportunities

It is important that Myrovlytis Trust's trustees act as advocates and ambassadors of the charity externally, as this can lead to new funding and partnership opportunities, as well as helping to promote the work Myrovlytis Trust do.