

## **Candidate Pack - Executive Director**

## Welcome from the President

**Dear Applicant** 

Thank you for your interest in joining ASIF as our first Executive Director. This is an exciting time to be joining the charity. For some years ASIF has been growing - its membership, its turnover, its staff team and its global influence.

Since 2016, our membership has grown from 36 to 52 members and our annual expenditure on charitable activities has grown from £23k to £300k.

The Trustees feel that it is now the right time to take the organisation to the next level. This will be the main task for our new Executive Director. We have an excellent and dedicated staff team in place, however they welcome the prospect of new and inspirational leadership.

I joined ASIF because I am passionate about raising awareness of axSpA globally and I believe ASIF can help big and small organisations to improve the lives of patients in their countries.

Our new Executive Director will need to have the drive to increase and diversify funding and the vision to develop a business plan that is in line with the strategic plan – and the will to put all that into practice. They will need to work with a passionate and engaged Trustee Board and will tasked with developing key strategic partnerships and developing relationships with established and new stakeholders.

Below you will find more about ASIF and the role. If, having read this candidate pack, you feel you have the experience, skills and attributes that we are looking for, we very much look forward to hearing from you.

Zhivko Yankov President





## Information about ASIF

ASIF is an international membership organisation representing patient associations around the globe specialising in the support of patients with Axial Spondyloarthritis (axSpA). AxSpA is a painful chronic inflammatory disease that primarily affects the spine and sacroiliac joints. It is estimated it affects more that 1 in 200 people. Currently ASIF has over 50 members in over 40 countries across 6 continents.

ASIF's Mission is to advocate globally to improve the lives of people affected by axial Spondyloarthritis and related conditions. To grow, strengthen and empower our community, and to raise awareness around the world.

Founded in 1988, ASIF was for many years run by its Trustees. ASIF registered as a charity in the UK in 2017 and employed its first member of staff. The staff team has now grown to 4 who together work the equivalent of 2 full time members of staff.

One of the most important events in ASIF's calendar is its Council Meetings which take place currently every two years. Members welcome the opportunity to meet face to face to share ideas and information and to network.

In addition ASIF manages a number of projects which aim to promote awareness of axSpA and improve the quality of life for patients with axSpA worldwide. These projects include:

**World AS Day –** An annual event that takes place on the first Saturday after 1 May each year. ASIF leads a global campaign of events and awareness raising.

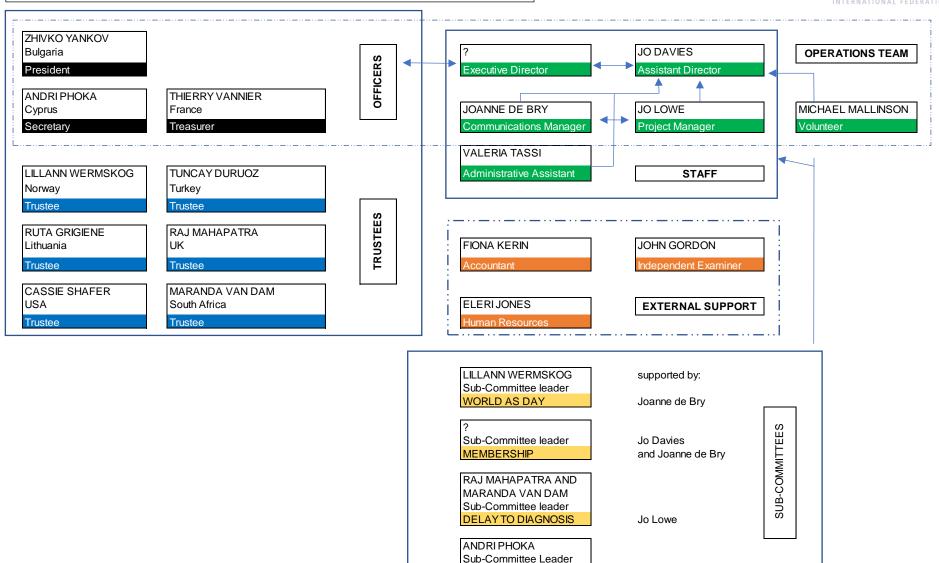
**Delay to Diagnosis** – It is known that globally there is an average of over 7 years from onset of symptoms to diagnosis. The delay to diagnosis can have a severe impact on the patient's quality of life. The first part of ASIF's Delay to Diagnosis project focussed on understanding the reasons for the delay and produced a Global Burden Statement. The next phase of the project, now underway, includes the development of delay to diagnosis content for members and the creation of a delay to diagnosis best-practice repository.

**IMAS –** The International Map of Axial Spondyloarthrits. IMAS is a world-wide patient survey that provides evidence about how people with axSpA experience the disease physically, psychologically and socially. IMAS aims to realise the voice of the axSpA community, ensuring patients around the world are empowered to live happy and well. We have just completed the global element of the survey and are in the process of working with members and the sub-committee to decide how the data can best be presented and used.

**Membership Resources –** We are developing a suite of tools. The first set aims to help patient associations to start up and to develop and the second set includes basic information about axSpA and living well with the disease.

# **ASIF Organisation Chart**





IMAS

Jo Lowe



## **ASIF Strategic Plan**

The Trustees and Staff at ASIF have recently developed a new strategic plan which provides a 6-year roadmap that outlines ASIF's direction and priorities. Our Strategic Objectives are divided below into Community, External World and Organisation.

## **Strategic Objectives:**

## **Community**

AIM: To build a stronger, larger, more empowered, inspired and engaged community.

Strategic Objective 1 - Grow, strengthen and empower the community

To support the creation of new patient organisations and grow the membership and wider community. To be an information hub for the axSpA community; to encourage networking, knowledge exchange and collaborative projects that benefit the community.

**Strategic Objective 2** - Support member advocacy, communications and capacity building with reliable, robust and validated information

Better understand the needs of our members and support them with information and tools to underpin their work, helping them to develop and achieve their objectives. To provide clear and referenced information to support communications and advocacy.

#### **External World**

AIM: To improve awareness and understanding of axSpA (and its related conditions); bring about positive change in policies and practices; improve access to treatment and healthcare globally; increase our knowledge and understanding and become known as the global hub for information on axSpA.

**Strategic Objective 3 -** Increase our understanding of the global axial Spondyloarthritis landscape

To develop the knowledge base within ASIF to better understand the prevalence and presentation of the disease globally, and to understand the research landscape and its findings.

**Strategic Objective 4** – Foster partnerships with medical societies, researchers, global organisations working in related disease areas, global policy makers and other stakeholders.

To advocate for axSpA patients and patient organisations globally.

To identify and foster relationships with key people or organisations working on axSpA or related disease areas. To build an understanding of these landscapes and find areas of common ground that can help us expand our area of influence.



## **Strategic Objective 5** - Raise global awareness

To build a communications network across members, supporting collaborative awareness campaigns. Engage with other stakeholders and industry partners to drive campaign and project activity that raises awareness globally.

## Organisation

To be a professional, well-respected and well-funded organisation.

Strategic Objective 6 - Enhance ASIF's performance and increase capacity

To ensure that the structure of ASIF (governance, staff, Trustees, volunteers) is appropriate to the changing needs of the organisation and will enable us to achieve our goals. To establish more robust standards; and develop staff, volunteers and Trustees to grow the organisation to enable us to achieve the objectives in this strategic plan.

## Strategic Objective 7 - Increase ASIF's financial sustainability

To undertake more robust and longer-term financial planning in line with strategic objectives. To review and develop our current budgeting and reporting and to ensure security of ASIF's funds.



# Job Description - Executive Director

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ASIF's mission is to advocate globally to improve the lives of people affected by axSpA and related conditions. To grow, strengthen and empower our community, and to raise awareness around the world.

## Role Profile

ASIF has grown considerably in the last 5 years and whilst we are very happy with the success to date, we are now seeking an Executive Director – a new role – to take ASIF to the next level. To increase ASIF's knowledge, capability, credibility, and reputation. Our Executive Director will provide inspirational and values-led leadership to our organisation. They will guide us to achieve our strategic vision to increase stakeholder and public awareness and to disseminate knowledge of the disease around the world.

To achieve this vision, the Executive Director will be a leading voice of the organisation, representing us to external stakeholders.

They must be a relationship builder with both strategic and operational experience. This is a hands-on role. They will be responsible for developing and growing the current small but extremely high-performing team.

#### Role Responsibilities

They will:

- Be responsible to the Board of Trustees.
- Be responsible for the Assistant Director and their team of staff.
- Ensure that the affairs of the organisation are conducted to the highest standards of integrity, probity and governance and will ensure that it is run in an efficient and effective manner.
- Have full accountability for the implementation and development of the strategic plan.

  They will lead on the prioritisation of the business plan working closely with the Assistant Director to ensure adequate resources are in place to achieve those commitments.
- Oversee and take responsibility for all areas of activity within the organisation and together with relevant staff, sub-committees and trustees develop new, viable services and activities that meet the needs of our patient organisation members.



- Be an ambassador for ASIF, work with the President and Board of Trustees to develop and promote ASIF's work, through effective dialogue, driving partnerships and engaging with pharmaceutical and corporate sectors and other stakeholders and increasing ASIF's and axSpA's recognition on the international stage.
- Be responsible for managing the risk and finances of ASIF and the production of the budget and Annual Report and Accounts, working with the Assistant Director, external accountant and independent examiner. They will also be responsible for ensuring adequate insurances are in place.
- Ensure the operational manual of policies and procedures is developed and maintained.
- Play a leading role in attracting and diversifying funding for the future ensuring it is sufficient to support the strategic plan and the organisation. This will require a practical approach to identifying and sourcing funding and thinking beyond traditional routes.
- Support the Assistant Director in leading and developing the existing operational team. Develop the positive and inclusive working environment. Growing that team and building on the already good track record of member support and project management thereby improving the stability and capability of the organisation.
- Draw the President and the Board of Trustee's attention to matters it should consider and make decisions about, ensuring proper attention is given to these issues. They will also ensure that the Board is given the advice and information necessary to perform its duties and work with the President to ensure the business of the Board is effective.
- Advise the President and the Trustee Board on constitutional matters ensuring compliance with the charity commission and other regulatory authorities.
- Be responsible for the implementation of the Trustee Succession Plan, working with the President to identify skills gaps and to attract and develop effective Officers and Trustees.
- Act as a driver for equality, diversity and inclusion, ensuring that effective policies, procedures and the delivery plans and projects are in place and promoted.
- Foster a climate of openness, transparency and learning which encourages feedback from
  members and staff ensuring that it is listened to and acted upon. In addition, they will
  ensure that there is a robust and continuous process in place to raise staff engagement,
  providing opportunities and encouragement for staff to participate in decision making
  and the planning of delivery outcomes.

This list of principal responsibilities reflects the breadth of this post; it is not exhaustive and may be subject to change



# **Person Specification**

## Experience of:

- Leading an organisation and delivery of strategic objectives.
- HR, finance, operations business development and business planning.
- Improving organisational capacity, capability and development.
- Working through influence with a wide range of stakeholders and of developing strong, collaborative and productive working relationships with partner organisations.
- Communicating effectively to influence key stakeholder relationships.
- Developing and inspiring high performing teams.
- Managing significant financial and other resources.
- Managing a remote team effectively.

#### **Abilities**

- Lead and develop charities or membership organisations.
- Provide inspirational leadership across the organisation and externally.
- Ability to build effective working relationships with a diverse range of colleagues, stakeholders, partners and the public.
- Excellent communication, interpersonal and analytical skills with a natural ability to adapt their style to the audience, issue and desired outcome.
- A confident public speaker.
- Managing a team including setting and monitoring objectives against performance to maximise contribution.
- Fluent in English.

#### Personal Attributes

- Champion and ambassador for the work and mission of ASIF.
- A compassionate and visible leader who is uncompromising when it comes to the delivery of the highest standards.
- An ability to plan with vision and creativity.
- Visible and assuring, an individual with intellectual rigour and the ability to analyse complex issues, to think and plan strategically and to exercise sound judgment in the face of conflicting pressures.
- Give confidence that inspires and builds effective teams.
- Effective communicator and influencer.
- Prepared to work flexibly.



## Salary, Benefits and Working Arrangements

The staff team all work remotely. This role too, will be remote with some occasional international travel.

Due to the nature of this role working across various time zones, the post holder will be expected to work flexibly with an expectation to be available outside normal working hours, during the evening and occasional weekends.

The role will be part time initially at 3 days per week with the potential to increase in due course.

Salary: £65,000 - £80,000 pro rata

Permanent, part-time, initially 3 days per week

# **Application process with timescales**

To apply for the position of Executive Director, please provide:

- 1. Your CV (maximum two sides)
- 2. A short supporting statement (maximum two sides) that sets out how you meet the job description above and why you would like to apply for the position of Executive Director of ASIF.
- 3. Your telephone and email contact details.
- 4. Any dates you are not available or where you may have difficulty with the indicative timetable below.
- 5. The names, positions, organisations and contact details of two referees, one of whom should be from your current or most recent position. We would not approach these referees before the panel interview stage, and only with your permission. If you do not wish us to approach your referees at any stage, please state this clearly.

Please email your application to: <a href="mailto:applications@asif.info">applications@asif.info</a> by 5pm on 20 September 2022.

If you would like a confidential and informal chat about the position, please contact Jo Davies, Assistant Director, on <a href="mailto:office@asif.info">office@asif.info</a>

**Deadline for applications:** Tuesday 20 September 2022

Candidates notified of outcome no later than: Friday 30 September 2022

**Longlist Interviews:** 11,12,17,18 October 2022

**Panel Interviews**: 2-9 November 2022

**Final Interviews**: 21-25 November 2022