

HEAD OF PHILANTHROPY AND MAJOR DONOR LEAD, UNITED STATES

FOLLICULAR LYMPHOMA FOUNDATION LOCATION — REMOTE, USA



Aspen Leadership Group is proud to partner with the Follicular Lymphoma Foundation in the search for a Head of Philanthropy and Major Donor Lead, United States.

The Head of Philanthropy and Major Donor Lead, United States will lead the development and delivery of the foundation's United States fundraising activities, engaging major individual and organizational donors through meticulously planned cultivation events and the careful stewardship of relationships that result in long-term partnerships with donors in support of the shared ambition of finding a cure for Follicular Lymphoma.

No one deserves to live with an incurable cancer. The Follicular Lymphoma Foundation (FLF) is changing that. FLF is the first charity dedicated to finding a cure for Follicular Lymphoma (FL). Follicular Lymphoma is a type of blood cancer affecting hundreds of thousands of people across the world. Follicular Lymphoma is the second most common Non-Hodgkin Lymphoma, yet despite its prevalence, most people have never heard of it. This means it is not getting the attention or funding it deserves. Follicular Lymphoma is not like most other cancers. For most people, FL is not an aggressive disease. People with FL will go through periods of active disease, followed by remissions. Living with Follicular Lymphoma causes a range of physical and emotional challenges, as well as confronting the uncertainty of not knowing when and how the cancer will return. Around a fifth of people with Follicular Lymphoma will develop an acute form of the disease which can be highly resistant to treatment and have poor outcomes for patients. Follicular Lymphoma is currently incurable, but the FLF is committed to changing that for patients living with FL now and for those who will be diagnosed in the future.

The Follicular Lymphoma Foundation understands the fear, the challenges, and the uncertainty that an FL diagnosis and ongoing treatments bring. The Follicular Lymphoma Foundation was launched in the summer of 2019 by founder Nicola Mendelsohn, who was diagnosed with FL herself in November 2016. At the time, despite being the second most common Non-Hodgkin Lymphoma, there was very little information available about Follicular Lymphoma for Nicola. During her search to understand her condition better, Nicola connected with the *Living with Follicular Lymphoma* Facebook group. Here she had the opportunity to be part of a community of others who shared her journey, and who shared their own insight, advice, and support. The group has over 8000 members globally—a close-knit online community of people going through the same journeys. Over time, Nicola became more involved in the stories and experiences of the individuals in the group as well. This led her to develop relationships with leading clinicians and investigators in the field, who convinced her that by raising awareness and funds, so much more could be done to transform the lives of FL patients and find a cure. Driven by her passion to make a difference to people living with Follicular Lymphoma and find a cure for this disease, the Follicular Lymphoma Foundation was established.

The mission of the Follicular Lymphoma Foundation is to find a cure and find it fast. Follicular Lymphoma is far from a new disease. Although first diagnosed almost a century ago in 1925, progress in the treatment of Follicular Lymphoma has been frustratingly slow. This is too slow for people living with this condition. Research and science have progressed rapidly—survival rates for some cancers have increased dramatically—yet FL receives comparatively little funding and little attention.

From the discovery of monoclonal antibodies nearly 50 years ago, it took until 1997 for approval of the first therapeutic monoclonal antibody—which has had a significant impact on extending the lives of people living with Follicular Lymphoma. Another 20 years has gone by with only a few new drugs proving successful in extending the length of remission from the disease, while the overall impact on survival rates has been negligible. There continues to be great excitement about new types of treatments including CART cells, antibodies that activate the immune system and molecularly targeted drugs. But it is not enough. People living with Follicular Lymphoma deserve greater certainty in their future, and this can only be achieved by finding a cure.

With the right resources and the right people, plus the best and most advanced research programs, a cure will be found—and fast. The FLF leads new and determined efforts to find innovative treatments and cures for Follicular Lymphoma. In pursuit of this, the CURE FL Awards grant program seeks to catalyze scientific research focused on FL. By focusing on high-impact studies this program supports a clear path to clinical trials and the hope of clear benefit and impact for FL patients. FLF Centres of Excellence is creating partnerships with major and prestigious academic and research institutions around the world with significant skills in FL and in many other disciplines that build on strong multi-disciplinary approaches to help the FLF achieve its mission to find a cure for FL. The FLF's Precision Medicine Programme (PMP) is a ground-breaking initiative mobilizing the Follicular Lymphoma patient community to fuel a targeted acceleration in FL research and clinical development. The PMP will leverage real-world data, including biological data to promote new directions in FL research and will drive biopharma and industry drug development with a goal to improve treatment strategies and to speed up the development of new treatments and ultimately a cure for every FL patient.

The aim of the Follicular Lymphoma Foundation is that by the 100th anniversary of the first diagnosis of Follicular Lymphoma there will be a path to a cure including better and less toxic and debilitating treatments that improve the personal journey of every patient.

REPORTING RELATIONSHIPS

The Head of Philanthropy and Major Donor Lead, United States will report to the Director of Fundraising, Tom Keil.

FROM THE DIRECTOR OF FUNDRAISING

Thank you for your interest in joining us on our critical mission—which is a determination to push as rapidly as possible for new treatments, that not only improve and extend the life of patients with Follicular Lymphoma, but that cure the disease once and for all.

Over the coming year, we will be accelerating the range and scale of opportunities for people to get involved with the FLF and support our mission in our work in the United States, in parallel with our work in the United Kingdom. Accompanying this will be an increase in the ways in which we can recognize and publicly thank donors and supporters. Building on the strength of our global fundraising program development to date, and the fantastic support of the FLF community so far, we are raising our 2024 ambitions—to raise \$12 million—to continue to grow our programs and invest strongly in the most likely routes to a cure for Follicular Lymphoma. This marks a significant scale up of our current operation and programming.

I am now seeking to appoint a Major Donor Lead in the United States to drive our fundraising program in the United States, to steward our existing relationships with those valuable major donors who have supported us thus far, and to cultivate new relationships. You will be that major donor fundraiser who can be trusted by our founders with our most important and influential supporters, and someone who is genuinely motivated by our mission and our ambition.

Together we can change lives. I look forward to our meeting.

—Tom Keil, Director of Fundraising

PRIMARY RESPONSIBILITIES

Fundraising Strategy

The Head of Philanthropy and Major Donor Lead, United States will

- lead the development and delivery of the United States fundraising strategy, designed to increase revenue from individual major donors, trusts, and foundations based in the United States;
- in partnership with the Director of Fundraising and the senior management team, draw up a roadmap for fundraising in the United States;
- develop and maintain agreed upon funding targets and the relevant key activity performance indicators that will deliver the required results;
- contribute to the production of both broad and targeted fundraising collateral, and work with colleagues to ensure that the foundation's case for support in the United States is backed up by quantitative and qualitative data; and
- contribute to annual United Kingdom fundraising program budgeting and forecasting.

Fundraising Delivery

The Head of Philanthropy and Major Donor Lead, United States will

- manage United States fundraising activities, translating the fundraising strategy into tangible income generation;
- produce compelling funding proposals to individual donors, corporations, and grant making organizations;
- develop and deliver a calendar of planned donor cultivation events throughout the year; and
- collaborate with communications colleagues to ensure that major partnership cultivation and stewardship are supported by appropriate collateral materials.

Major Donor Relationship Development and Management

The Head of Philanthropy and Major Donor Lead, United States will

- develop and maintain productive personal relationships with existing and potential United States based major donors, maintaining engagement, securing new support, and maximizing potential contributions;
- research and identify potential donors including individual philanthropists, decision makers in corporations, trusts, foundations, and other grant making bodies, and craft the appropriate approach plan and execution;
- build relationships with existing United States based major donors, corporations, trusts, and foundations and take on the responsibility for maximizing ongoing giving potential;

- create, implement, and monitor events and other means of donor engagement that secure a pipeline of new major donors;
- work with the Director of Fundraising on key existing and future ultra-high-net-worth relationships; and
- work with internal measures that are in place for effective donor stewardship, including acknowledging donors for their support and providing reports, and enhancing these measures where necessary in pursuit of excellence in donor stewardship.

Governance and Administration

The Head of Philanthropy and Major Donor Lead, United States will

- ensure effective governance and administration of United States fundraising activities;
- ensure that all fundraising activities are compliant with relevant United States charity and other statutory legislation and conform to relevant requirements;
- along with the Director of Fundraising, provide expert advice and guidance to the foundation's founders and the Board of Trustees and coordinate any secretariat support required;
- provide timely financial performance monitoring, produce regular income forecasting reports, and risk adjustment updates based on confidence levels;
- track the volume of activity, number of emails/calls with major donors, submissions to trusts and foundations, etc. in order to monitor opportunities as they move towards closure;
- ensure that the fundraising CRM donor management database is used to manage activity and monitor progress effectively; and
- ensure timely response and follow up to major donors, including gift receipts and thank you notes, aligned with the internal measures set.

LEADERSHIP

Tom Keil

Director of Fundraising

Tom Keil joined the Follicular Lymphoma Foundation from Cambridge University, where he worked as the Senior Associate Director leading the university's cancer philanthropy. This included being responsible for a £50m capital campaign, designed to support the new Cambridge Cancer Research Hospital. Prior to Cambridge, Tom worked at King's College London where he again led the university's cancer philanthropy programme. He holds an MA from King's College London in Conflict Resolution in Divided Societies and is also an alumnus of Cardiff University.

Tom is the first Director of Fundraising at the FLF and is responsible for the charity's income streams. Tom brings with him a wealth of fundraising experience, with his expertise being in the major gift and principles gift spaces. Tom is passionate about connecting with prospective supporters, listening to their incredible stories, and helping to connect them to the work of FLF. Tom's primary goal is to help galvanize FLF's fundraising activities, as it is this that will drive the charity's programmes and allow it to create a new future for patients with follicular lymphoma.

PREFERRED COMPETENCIES AND QUALIFICATIONS

The Follicular Lymphoma Foundation seeks a Head of Philanthropy and Major Donor Lead, United States with

- a commitment to the mission of the Follicular Lymphoma Foundation—to help those with Follicular Lymphoma, a currently incurable blood cancer, to live well and get well by finding and funding the best research to find breakthroughs that will change how Follicular Lymphoma is understood and treated;
- strategic and operational experience with major donor fundraising including personal responsibility for successful solicitations with significant institutional impact from individual philanthropists, corporations, trusts, foundations, and other grant making entities;
- an ability to influence and persuade, negotiate with, and work in collaboration with high-level donors and their intermediaries;
- experience delivering upon major donor cultivation activities, including high-profile events that are fully supported by timely and relevant marketing and communications;
- knowledge of current trends in major donor giving and the regulatory framework for fundraising in the United States;
- excellent oral, written communication, and presentation skills across multiple platforms;
- empathy and an ability to inspire, motivate, and build effective working relationships with major donor, volunteers, scientists, researchers, colleagues, and other stakeholders;
- strategic planning and organizational skills including an ability to produce strategic and operational plans, manage projects, and ensure appropriate fundraising administration processes;
- financial acumen including budgeting and forecasting;
- analytical skills including an ability to identify and evaluate fundraising options, using financial and other performance management data to inform decisions;
- an ability to develop and implement creative solutions to complex challenges;
- an ability to work both independently and collaboratively; and
- experience with fundraising databases.

A bachelor's degree or an equivalent combination of education and experience is preferred for this position as is at least five years of fundraising experience, with an emphasis on healthcare. The Follicular Lymphoma Foundation will consider candidates with a broad range of backgrounds. If you are excited about this role and feel that you can contribute to FLF, but your experience does not exactly align with every qualification listed above, we encourage you to apply.

LOCATION

This is a fully remote position based in the United States. FLF's offices, and the bulk of its programmatic activities, are based in London. This role will be best executed by an individual living in the eastern time zone of the United States to facilitate collaboration with the London-based team. An ability and desire to travel is essential.

SALARY

The salary range for this position is \$95,000 to \$110,000 annually. The Head of Philanthropy and Major Donor Lead, United States and FLF will come to a mutual agreement to provide benefits, including health insurance. The position will be compensated for 25 vacation days, 10 sick days, and 10 holidays annually.

APPLICATION INSTRUCTIONS

All applications must be accompanied by a cover letter and résumé. *Cover letters should be responsive* to the mission of the Follicular Lymphoma Foundation as well as the responsibilities and qualifications presented in the prospectus.

To apply for this position, visit: <u>Head of Philanthropy and Major Donor Lead, United States, Follicular</u> <u>Lymphoma Foundation</u>.

To nominate a candidate, please contact Clare McCully: <u>claremccully@aspenleadershipgroup.com</u>.

All inquiries will be held in confidence.