

## TRUSTEES' ANNUAL REPORT

<b>PERIOD:</b>	Financial Year ending 31 <sup>st</sup> March 2020 (the <b>Reporting Period</b> )
<b>CHARITY NAME:</b>	Ewing's Sarcoma Research Trust (as the <b>charity</b> or <b>ESRT</b> )
<b>REGISTRATION NO.:</b>	1145849
<b>PRINCIPAL ADDRESS:</b>	7 Goldfinch Close, Paddock Wood, Tonbridge, Kent TN12 6XW
<b>TRUSTEES:</b>	Elaine Phillips, Colin Short, Matthew Short, Nigel Short, Louise Twist and Martin Waite (the <b>Trustees</b> )

### OBJECTIVES AND ACTIVITIES

#### *Objectives*

The charity's Declaration of Trust Deed originally dated 21 June 2011 (as amended on 18 June 2017) sets out its primary goals:

1. the advancement of the education of the general public and the promotion of research for the public benefit in all areas relating to Ewing's sarcoma (and the publication of the useful results of such research); and
2. the preservation and protection of the physical and mental health of people suffering from Ewing's sarcoma by providing and assisting in the provision of equipment, facilities, services, information, support, education, practical advice and other such assistance.

#### *Activities*

During the Reporting Period, the charity continued with its practice of not organising and/or co-ordinating fundraising events, while seeking to actively support fundraisers (including by providing administrative backing and supplying branded merchandise) in their fundraising efforts for the charity. The charity has terms and conditions governing the use of its logo and takes reasonable steps to safeguard against improper use.

The charity maintains commercial relationships with a limited number of organisations that operate in the fundraising sector and facilitate the collection of donations or fundraising efforts of individuals. All such relationships are based on written contracts and customary terms and conditions of each organisation.

The charity is committed to continuing to provide its supporters and fundraisers with assistance and guidance to facilitate their fundraising activities. This support extends to promoting awareness amongst donors. The charity has fundraising terms and conditions that are communicated to fundraisers and takes such other steps as the trustees deem appropriate to make fundraisers aware of their responsibilities in undertaking fundraising for the benefit of the charity.

### ACHIEVEMENTS AND PERFORMANCE

#### *General*

The charity continues to promote awareness of this disease through information published on its website and fundraising activities.

Following the discontinuation of the Information Standard by NHS England in July 2019, ESRT has remained committed to providing evidence-based health information for the public, based on the principles previously enshrined in the Information Standard.

The charity continues to work closely with the Bone Cancer Research Trust (BCRT) and collaborates on joint initiatives relating to Ewing's sarcoma research and promotion of awareness of the disease amongst groups most at risk. The two charities continued to work closely during the Reporting Period and the ongoing working partnership continues to show positive outcomes for both.

ESRT remains open to the possibility of developing further partnerships with other charitable organisations involved with Ewing's sarcoma, where appropriate due diligence and partnership discussion has been completed, identifying the potential for mutually beneficial working relationships that are advantageous to both organisations and the wider goal of improving outcomes for Ewing's sarcoma patients.

#### *Funded research and initiatives*

1. Research into Ewing's sarcoma stem cell-like cells by the Children's Cancer Research Group at Leeds Institute of Cancer and Pathology (the **CCRG**)

In March 2018, ESRT committed to funding research which aimed to better differentiate between patients, to enable the identification of cells which are responsible for causing a relapse or negative patient outcome following treatment for Ewing's sarcoma.

Initial funding was provided prior to the Reporting Period, however the CCRG have continued their research during the Reporting Period and have identified certain "drivers" which are considered relevant in determining the likelihood of relapse or poor response to conventional treatments. It is hypothesised that Ewing's sarcoma stem cell-like cells (**ES-CSCs**) play a role in treatment outcomes, and identifying existing treatments or novel treatments which are more specific in reducing the presence of specific drivers in these ES-CSCs (or killing cells where such drivers are present) could present a useful supplement to existing treatments to improve outcomes.

2. Research into use of Oncolytic Virus Therapy (**OVT**) in treating Ewing's sarcoma

ESRT had also committed to providing funding to support research into the use of OVT in treatment of Ewing's sarcoma prior to the Reporting Period. This research continued during the Reporting Period. The research aims to assess the use of OVT as a form of immunotherapy with two main goals: using the immune system to attack cancer cells directly, and using OVT to kill cancer cells whilst leaving healthy cells unharmed. Current treatment protocols are not sufficiently tailored to be able to attack only cancer cells, and as a result traditional chemotherapy causes damage to otherwise healthy cells.

Whilst this project is laboratory based, it is using a form of OVT which has been tested on other cancers (including in studies demonstrating it is capable of safe use in human patients). This offers the promise of a shorter time period to progress initial studies to larger-scale, clinical trials in humans.

During the Reporting Period, researchers have identified three different OVTs which have shown promise in activating the immune system to attack laboratory-cultivated Ewing's sarcoma cell lines – including cell lines that are resistant to doxorubicin (a drug used in current protocols). This offers the possibility of OVT being used with other treatments for drug-resistant Ewing's sarcoma (i.e. in patients with negative responses to treatment or in instances of relapse).

Researchers have also commenced another phase of research aimed at combining the use of antibodies with OVT. Use of antibodies offers the possibility of blocking signals which Ewing's sarcoma cells emit, which otherwise would reduce the ability of immune cells to attack Ewing's sarcoma cells.

The research project will move on to testing OVT in patient samples (as opposed to laboratory cultivated cell lines), as these offer a more representative model of Ewing's sarcoma. This stage will also involve other cell types which commonly surround Ewing's sarcoma cells in live patients, to combat their role in tumour proliferation and metastasis.

### 3. Funding of Euro-Ewing Consortium (EEC)

During the Reporting Period, the charity committed to funding, and funded its full commitment to funding, the work of the EEC. The EEC was initially established in 2014 and benefitted from funding from the European Union until November 2019. It continues to be co-ordinated by University College London's Cancer Institute. The EEC brings together clinicians and researchers from across Europe to support an integrated programme of investigator-driven clinical trials supported by complementary embedded translational research.

ESRT's support has enabled the EEC to continue to operate following the expiry of EU funding, and supports the role of scientific project manager, a role which brings together responsibility for facilitating networking, disseminating information to researchers and carrying out financial management for the EEC.

The EEC met in January, in a meeting that was widely attended and has been followed by substantial online collaboration by members in light of travel restrictions arising from COVID-19.

#### *Further funding opportunities and activities*

During the Reporting Period, ESRT issued a research call in collaboration with BCRT offering a grant up to £100,000 for a suitable Ewing's sarcoma research project. A number of applications were received, however, after consultation with BCRT, it was determined that the applications did not satisfy the required grant criteria and no funding was advanced. The charity remains committed to financing or contributing to suitable research in the future, should the right opportunity arise.

Other small grants have been approved to support initiatives linked to Ewing's sarcoma research, for example supporting a post-doctoral researcher's secondment to BCRT to help to increase sample availability for Ewing's sarcoma research.

### **FINANCIAL REVIEW**

A copy of the charity's Accounts for the Reporting Period is attached to this report.

The Accounts show an annual income of £20,671.56. The charity remains indebted to its numerous fundraisers who continue to provide significant support through their fundraising activities. The Trustees recognise that this represents approximately 50% of annual income for the financial year ending 31 March 2019, however, in light of adopted financial management strategies and policies, the charity's assets exceed its committed liabilities, with a substantial contingency budget.

During the Reporting Periods, the trustees have continued with their existing strategies and policies set out in further detail below with the intention of ensuring the ongoing ability to operate the charity in a financially sound manner and considered these strategies appropriate during the Reporting Period.

The principal source of income remains donations and monies raised by the charity's supporters (including, where eligible, Gift Aid payments on these donations received from HM Revenue & Customs).

Disbursements made in respect of previously approved grants during the Reporting Period amounted to £48,977.21. Third party costs incurred by the charity in pursuance of its goals amounted to £651 only during the Reporting Period.

The charity has traded during the Reporting Period without incurring any internal costs, and in doing so has committed to ensuring that the vast majority of funds raised can be used in furtherance of its charitable goals. Again, no costs were attributable to trustees' activities.

At the end of the Reporting Period, the charity's cash assets constituted £212,718.11, including the £36,726.54, being funds allocated to settle commitments made pursuant to grants where instalments have not yet become payable (such amounts will only become payable to the extent the beneficiary incurs such costs in accordance with the terms of the applicable grant).

At the end of the Reporting Period, the charity committed to providing significant research funding towards projects arising from a Ewing's Sarcoma Symposium, which was initially scheduled to be held in summer 2020. In light of the COVID-19 pandemic, the event will be rearranged, but the charity remains committed to providing the funding towards projects arising from the event. The symposium will be facilitated by a lead researcher from the Children's Cancer Research Group at the Leeds Institute of Cancer and Pathology with the support of BCRT. Leading researchers from various countries have been invited to participate.

The trustees continue their policy of declining to commit to funding obligations where doing so would result in the charity's liabilities exceeding its liquid assets (after agreeing a suitable amount of funds to be retained at all times as contingency funding). The trustees remain of the view that the charity must always maintain sufficient funds to meet all binding financial obligations. At the end of the Reporting Period, other than the aforementioned £36,726.54, ESRT had no other current obligations. The charity has no outstanding debts.

The trustees have agreed that the majority of funds will be held in a bank savings account, but all or some of these funds may be temporarily invested in non-speculative financial investments, such as Money Market accounts where there is no risk to the principal sum(s) invested.

The trustees remain mindful of the compensation available through the Financial Services Compensation Scheme. The Board have agreed that sums held in excess of the maximum amount of compensation covered by the scheme may be deposited with other banks within this scheme should the credit rating of the current financial provider necessitate this precautionary measure.

## **STRUCTURE, GOVERNANCE AND MANAGEMENT**

The charity is managed solely by the trustees, who are all volunteers. No other staff or volunteers currently assist in the running of the charity.

The charity is constituted as a Charitable Trust under HM Revenue & Customs regulations.

Prior to their appointment, trustees will sign the standard declarations required by the Charity Commission; the 'Fit and Proper Persons' Declaration, the Automatic Disqualification Declaration and Trustee Eligibility Declaration.

Prior to the appointment of a trustee, a check is made to ensure that a prospective trustee is fit to serve by checking that they do not appear on Companies House - Register of Disqualified Directors,

or the Charity Commission - Register of Removed Trustees, or the Insolvency Service - Individual Insolvency Register. The status of all trustees is checked against these registers at the beginning of each financial year.

The Deed of Variation to the charity's Declaration of Trust Deed stipulates that there shall be a least three, but no more than fifteen trustees. Every Trustee shall hold office for a term of three years, renewable by re-appointment for further terms of three years each. A Trustee who has served for two or more consecutive terms shall remain out of office for at least one year before he or she may be re-appointed. However the Trustees may decide to disapply this restriction in respect of any Trustees having due regard to the skills and experience required by the Trustees collectively at the time. During the Reporting Period, this right was exercised and one of our Trustees, who had served for consecutive terms totalling six years, was unanimously re-appointed.

The charity must hold at least two formal meetings during the year.

During the Reporting Period the trustees convened on three occasions; minutes of all meetings are produced and circulated for acceptance by trustees in attendance. The meetings are used to plan, organise, control and manage the activities of the charity and ensure compliance with the terms of the Declaration of Trust Deed, as amended by the Deed of Variation.

The partnership with the BCRT and the charity continues to be governed by a Memorandum of Understanding, which documents the arrangements for funding Ewing's sarcoma research where approved by BCRT's Independent Scientific Advisory Panel and their Board of Trustees. The terms of this arrangement are subject to periodic review to ensure that it continues to meet the aspirations, goals and requirements of both charities.

The charity's trustees declare that they have complied with their duty to have due regard to the guidance on public benefit published by the Charity Commission in exercising their powers and duties.

The charity's activities necessitate the retention of personal data. Consequently, the charity maintains its registration with The Information Commissioner's Office under Registration reference ZA139624.

The website privacy policy reflects current regulations and the charity continues to use a third-party provided email server that offers security which the trustees, having considered the security provided, to be appropriate to meet the charity's obligations.

The trustees are mindful of the obligation to ensure the safety of children and vulnerable adults who come into contact with the charity. Currently the charity has not insisted upon trustees undergoing an Enhanced DBS check as, in their day-to-day duties, trustees do not come into contact with vulnerable groups and consequently checks are not deemed to be necessary. This policy is the subject of regular consideration and the trustees agree that Enhanced DBS checks should be carried out where it is desirable and appropriate. Should circumstances change the policy will be reviewed. Certain of the charity's trustees currently work in environments where periodic DBS checks are mandatory.

Current policies and procedures continue to be the subject of regular review and will be updated should the need arise.

The charity will make use of advice and guidance published by The Charity Commission to ensure that it is able to maintain its charitable status.

## REFERENCE AND ADMINISTRATIVE DETAILS

At the end of the reporting period the six serving trustees were:

1. Colin Short
2. Elaine Phillips
3. Louise Twist
4. Martin Waite
5. Matthew Short (Founding Trustee)
6. Nigel Short (Chair of Trustees)

The trustees remain committed to recruiting appropriate individuals to assist in furthering the charity's goals. Trustees remain aware of the need to identify and recruit suitable replacements going forwards.

The charity recognises the need to ensure a diverse spread of trustees with different skills and backgrounds to ensure the charity proceeds on a solid footing.

## EXEMPTIONS FROM DISCLOSURE

There are no exemptions from disclosure.

## FUNDS HELD AS CUSTODIAN TRUSTEE ON BEHALF OF OTHERS

No funds are currently held on a custodial basis.

## DECLARATION

The Trustees declare that they have approved this trustees' report above.

Signed on behalf of the charity's trustees

Name: Nigel Short

Position: Trustee

Date: 15/08/2020

Signature:



Name: Louise Twist

Position: Trustee

Date: 15/08/20

Signature:

