#### **OVERVIEW**

The goals of the Diana's Fibroid Foundation (DFF), a qualified 501(c)(3) tax-exempt organization, are aimed at providing funding for research and education focused on the potential for malignant cells associated with or harbored by uterine fibroids (leiomyomas), which are generally described as benign but understates the risk and impact on patients and their families.

Research funding is anticipated to be provided for the following aims:

- Improve the understanding of the biology and etiology of malignant cells originating and/or harbored in fibroids
- Identify risk factors associated with potential of fibroids to harbor malignant cells
- Investigate and/or advance methods for early detection of malignancies

#### **LEADERSHIP**

Blake Tomkinson, MBA, PhD Donald Tomkinson, MBA Heather Vital, SM, MBA Kaleigh Tomkinson, MS, DO

# **DIANA'S STORY**

Diana's Fibroid Foundation (DFF) was established to honor our beloved Diana Leigh Tomkinson by advancing detection and understanding of the underlying causes of malignancies that may clinically imitate uterine fibroids or the potential malignant transformation of a fibroid. Diana fought a difficult and courageous battle for nearly 4 years with a dedicated medical and family team chasing her malignancy in the abdomen, lung, brain and eventually the spine. Despite the challenges, she remained ever hopeful that the next therapy would manage her disease but ultimately, she lost her battle on February 19, 2020 surrounded by her family.

Diana's experience was similar to many women that are diagnosed with uterine fibroids—with a critical exception—her fibroids were hiding a malignancy that would eventually take her life at 60. She was diagnosed with uterine fibroids in her 40s and went through multiple embolization procedures to control the fibroid growth and associated symptoms before deciding to undergo a hysterectomy. Unfortunately, during the preoperative workup, a 12 cm mass in her abdomen was identified. The mass was eventually diagnosed as a rare sarcoma, perivascular epithelioid cell neoplasm (PEComa). It metastasized to the lung, brain, and spine, making for an incredibly difficult battle.

Diana ultimately endured 11 treatments, both chemotherapy and targeted agents, 2 brain surgeries, and 12 rounds of radiation—often with encouraging response but ultimately short-lived with regrowth in each location.

Early detection of malignant cells hidden by fibroids is critical to prevent the devastation our family endured. With your support, we hope to advance education and early detection to help other families' wives, mothers and grandmothers avoid the same struggle as our Diana



#### **FUNDING SOURCES**

## **Family Contributions**

Initial founding funds

#### **Public Donations**

- Friends of the family
- The Diana Tomkinson Memorial Fund established following Diana's death and donations delivered via GoFundMe
- Donate via Web site

## **Charitable Organizations**

- Other organizations/foundations with similar objectives
- Charities and organizations focused on oncology and women's health

## **Industry Collaborators**

- Pharmaceutical companies with shared goals
- Matching contributions and/or donations of employers

With your investment, we can change the outcome for women with malignancies potentially hidden by fibroids.
Donations may be made at dianasfibroidfoundation.org or via the QR code below.



## **EDUCATION OBJECTIVES**

Education efforts will include compiling and creating content to increase awareness of the risk of malignancy in a uterine tumor clinically diagnosed as a fibroid. This will include creation of a patient-focused website to provide a platform for education and public reference. It will include, at a minimum, details of Diana's story, education links for fibroids and malignancies, key scientific links, links to other women's health websites, as well as a link to PayPal Account to accept donations.

In addition, the DFF will engage with other organizations in the uterine fibroid, gynecology, women's health, and cancer spaces to improve recognition and recommended treatment considerations of potential malignancies associated with fibroids.

#### **RESEARCH GRANTS**

Single year grants provided for research projects that require limited funding, for example, procure and screen fibroids for early detection, new or improved imaging techniques, detection and quantification of circulating tumor DNA in blood.

Multiple year grants to support investigation of the biology, etiology and association of malignancies with fibroids as well as more involved early detection and techniques that may require more funds and research time.

Grants to non-profit organizations to educate women regarding the potential malignancies associated or harbored by fibroids.

## **RECENT INVESTMENTS**

The DFF provided its first research grant on Diana's birthday, October 17, 2020, to the Northwestern University Feinberg School of Medicine. The gift in the amount of \$100,000 over 2 years is for the purpose to research and explore the molecular relationship of benign uterine leiomyomas and uterine malignant leiomyosarcomas.

