

PRESS RELEASE

October 2013

Sarcoma UK announces partnership with new sarcoma support organisation in Northern Ireland

Sarcoma UK is delighted to be working in partnership with the Boom Foundation in Northern Ireland. Boom was launched in spring 2013 in memory of Philip Wilson who sadly lost his battle to sarcoma in March that year, just seven weeks before he was due to get married. His fiancée Leona Rankin set up the Foundation with the aim of filling the gaps in the support available for patients and their families.

The Boom Foundation aims to raise public awareness and funds, of which 50% will go towards support initiatives in Northern Ireland including a new sarcoma support group for patients and families and financial grants for individuals and families. The other 50% will go to Sarcoma UK to support its nationally-focused work to improve standards of treatment and care for patients in the UK and to fund vital research.

Leona Rankin, founder of The Boom Foundation said:

“Sarcoma UK played a hugely supportive role to Philip and I throughout his illness and through The Boom Foundation we hope to give this charity the recognition that it deserves whilst offering local support to those affected by sarcoma throughout Northern Ireland. We are delighted to be working alongside a charity with such a vast amount of knowledge and expertise. I am confident that we will accomplish great things here in NI for those affected by sarcoma as a result of our partnership with Sarcoma UK.”

Lindsey Bennister, chief executive of Sarcoma UK said:

“We are so pleased to be working with Leona to improve the support available in Northern Ireland for sarcoma patients and their families. Despite the personal tragedy of losing her fiancée Philip, Leona is determined to make sure that other people have support available to them when diagnosed with sarcoma. We share the same objective of transforming the landscape for people affected by sarcoma in Northern Ireland and I look forward to a long and productive partnership.”

The Boom Foundation is holding a fundraising Gala Dinner on 30 November 2013 at Titanic Belfast. Information is available on the Foundation website.

For more information about The Boom Foundation, contact:

Leona Rankin, email: theboomfoundation@hotmail.co.uk, tel: 07540 896470.

Website: www.theboomfoundation.co.uk

Registered charity number: NI00145

Key messages

About sarcoma

- Sarcomas are rare cancers that develop in the muscle, bone, nerves, cartilage, tendons, blood vessels and the fatty and fibrous tissues
- There are around 100 different sub-types of sarcoma
- There are around 3,800 new cases of sarcoma diagnosed each year in the UK:
 - 3,330 people are diagnosed with a soft tissue sarcoma (including GIST)
 - 500 people are diagnosed with a bone sarcoma
- 10 people every day are diagnosed with sarcoma in the UK
- There are around 12,000 people living with sarcoma in the UK
- Sarcomas make up 1% of all cancer diagnoses in the UK
- Sarcomas make up 14% of all childhood cancers (0-14 years)
- Sarcomas make up 11% of all cancer diagnoses in teenagers and young people (15-24 years)
- In **Northern Ireland**, 100 new cases of sarcoma are diagnosed each year.
 - There were 83 cases of soft tissue sarcomas in 2010.
 - There were 17 cases of bone sarcomas in 2010.
- In **Scotland**, just under 300 new cases of sarcoma are diagnosed each year
 - Approximately 20 children and young people (0-24) are diagnosed with sarcoma each year
- In general, patients with a bone or soft tissue diagnosis tend to be younger than the majority of cancer patients
 - 16% of bone or soft tissue sarcomas are diagnosed in patients less than thirty years of age, compared to around 2% of all cancers *

- 37% of bone or soft tissue sarcoma patients are aged less than 50 years*
 - The five-year relative survival rate for all sarcomas is approximately 55%*
 - There has been no significant improvement in survival rates for bone sarcomas in the the last two decades*
 - There has been significant improvement in survival rates for soft tissue sarcomas (from 48% to 56%) in the last two decades *
- *England data

About Sarcoma UK

- Sarcoma UK is the main charity in the UK focusing on all types of sarcoma
- Sarcoma UK provides information and support for anyone affected by sarcoma –patients, carers, family and friends
- Sarcoma UK’s aim is to achieve the best possible standard of treatment and care for patients with sarcoma. It does this through:
 - Funding scientific and medical research into causes and treatments;
 - Delivering a range of support and information services covering all aspects of sarcoma;
 - Raising awareness of sarcoma amongst the public, healthcare professionals and policy makers;
 - Campaigning on behalf of sarcoma patients for improved treatment and care
- Sarcoma UK relies solely on voluntary donations and fundraising activities to fund its work
- Sarcoma UK is staffed by a small team of five, managed by a board of trustees (many with personal experience of sarcoma), and supported by experts in the sarcoma field
- Sarcoma UK works collaboratively with healthcare professionals and other cancer charities