FEATURE ARTICLE: ‘GET INSPIRED’
Lost and Found – On your Bike!
by Shirley Crisford

Ross Fenton is an inspiration and a biker! A hobby from teenage years that got lost and then found, as a result of suffering from prostate cancer. In his darkest moment, it turned his life around. Now he inspires fellow survivors to find what they have lost.

On February the 10th 2010 Ross was diagnosed with prostate cancer. His elder brother, already a sufferer, advised him to have a PSA test, even though Ross had no obvious symptoms. At the end of February he was whisked into hospital for a robotic prostatectomy followed by a three-week stay in hospital for a robotic procedure. From there he was whisked out of hospital and into the environment of bikers at Jack’s Café in Towcester, then Kent, until he had met online. A month later there was another small gathering of bikers at Jack’s Café in Towcester, then Kent, until ‘The Prostate Motor Cycling Club’ was born.

One day his wife gave him an ultimatum – to ride, or get rid of his bikes! Ross had to MOT and insure the bikes first before road testing them for sale. In doing so, he rekindled a passion that took him on the road; took him out of the house and, took his mind off his worries.

In April 2010 Ross set up his first Motorcycling Meeting in the iconic, Ace Café in Willesden with a fellow enthusiast he had met online. A month later there was another small gathering of bikers at Jack’s Café in Towcester, then Kent, until ‘The Prostate Motor Cycling Club’ was born.

Ross chuckles, “We call it the Prostate Meet-and-Chat Club”, where symptoms and worries are shared and our passion for biking shamelessly indulged. He says there are many official bodies that run large, formal functions for survivors. But, he argues, “They lack the intimacy and openness that comes with smaller, more informal groups, where trust is built and friends are made”.

Ross has given talks to other survivors on ‘The Meaning of Life after Prostate Cancer’. He shares his early experience of going through the motions of being a patient, “I felt like a passenger — that it was happening to somebody else”; to getting back in the saddle and taking control. “You can see yourself as a shadow of your former self, when you are just as capable as you were before”.

Ross is now looking to launch ‘Motor for Dad’, a psychosocial support network for fellow survivors; something, he argues, that is sadly lacking. But, can be found every 2 months on a Sunday morning with ‘The Prostate Motor Cycling Club’. He tells me he has found a new purpose in life and new skills. “Change your way of dealing with it”, “Master the art of not worrying” and, “Enjoy the life you have”.

He adds, “My participation in the UKGPCS made me feel I could do something to help, especially for my family and younger relations. It helped settle my mind.”

So, as our interview came to an end, I began to think — perhaps I need to get ‘On my bike’ and unleash a hobby. What do you think?

If you have a story to share with us for our feature article, ‘Get Inspired’, please contact the UKGPCS team on 020 8722 4395.
Aim of study: To determine the effect of screening men with a known mutation in BRCA1 or BRCA2 genes for prostate cancer.

Prostate cancer risk due to mutations in BRCA1/BRCA2 genes: These gene mutations are not common and primarily predispose to breast and ovarian cancer in women. However, a BRCA1 gene mutation may double the risk of prostate cancer in men aged under 65, and the BRCA2 gene mutation increases the risk of prostate cancer by up to 7-fold.

Recruitment eligibility: Men aged between 40 and 69 years who fall into 3 categories: (1) BRCA1 mutation carriers; (2) BRCA2 mutation carriers; and, (3) Controls - men who have tested negative for the BRCA1 or BRCA2 gene mutation, known to be present in their family.

Screening for participants: Annual prostate screening is offered in the form of a PSA (prostate specific antigen) blood test. A biopsy of the prostate gland is recommended if the PSA level is found to be higher than 3.0ng/ml. Medical and family history data are collected from all men, as well as blood and urine samples for research tests.

Recruiting: IMPACT has been running for 5 years. There are 37 centres recruiting into IMPACT worldwide with 13 centres in the UK. It has recently enrolled the 1000th participant and is looking to recruit a further 700 men into the study.

Published Findings: Results from the first 300 men enrolled in the study (205 with BRCA1 or BRCA2 gene mutations and 95 with no such gene mutation), detected 24 men with elevated PSA levels, who underwent a prostate biopsy. The biopsy results demonstrated that a higher proportion of gene mutation carriers had prostate cancer, than non-carriers. In addition, 78% of gene mutation carriers had intermediate or high-risk disease, requiring treatment. This compares with only 35% of men diagnosed with prostate cancer in a major population-wide screening study in 2009.

The study adds to the increasing evidence that BRCA gene mutation carriers develop more aggressive disease.

For more information about the study please contact:
Elizabeth Bancroft (or) Elizabeth Page on
Email: impact-study@icr.ac.uk
Tele no: 020 7808 2136/020 8661 3897
Or visit our study website: www.impact-study.co.uk

Our thanks to The Ronald & Rita McAulay Foundation
Welcome to the Uro-Oncology Clinical Trials Team, based at the University Hospital of Wales, Cardiff.

The aim of the unit is to improve the level of support available to Consultants engaged in research, in order to provide patients with better access to Clinical Trials.

The Uro-oncology Research team is led by Professor Howard Kynaston and is supported by Samantha Holliday (Lead Research Nurse), Clare Jones and Kevin Pearse (Research Nurses) with data support from Elizabeth Harris.

"...improve access to genetics services for people from minority ethnic communities in England."

Genetic Alliance UK in partnership with The Division of Primary Care at the University of Nottingham, have launched a new project that will identify:

(1) Why there is a significant under-representation of cancer referrals to clinical genetics services amongst people from minority ethnic groups; and

(2) What strategies and interventions could be developed to address this inequity.

The Team: Anna Allford (Research Assistant for Genetic Alliance UK) in collaboration with 2 NHS Clinical Genetics Services in England.

Investigating: The service experience of people from South Asian, Black Caribbean and White Irish communities.

Interviewing: Clinicians, other professionals, patient service users and the public.

Project funded by: Big Lottery Research Fund

How can you help?

By circulating posters, leaflets and details of this study to relevant organisations and support groups working within the above ethnic minority communities members who have:

(1) significant family history of prostate cancer, but will not have had a consultation with any genetic services;

(2) family history of the following common cancers:
  - Breast cancer (sometimes associated with a family history of ovarian cancer), or
  - Bowel cancer

For more information please contact:
Telephone: Anna on 07743 481794
Email: anna@geneticalliance.org.uk
Website: http://www.geneticalliance.org.uk/projects/ethnicityandaccess.htm
A MATTER OF GENES
UK Genetic Prostate Cancer Study Newsletter

Staff News — All Change!

Koveela Govindasami MSc – Study Co-ordinator
Koveela studied at the University of Westminster and University College London in Biotechnology and Genetics of Human Diseases. She worked as a Clinical Trial Scientist and Dental Practice Manager, before taking up the post of Study Co-ordinator in November 2010, replacing Dr Michelle Guy who is currently on maternity leave. Koveela was born in Mauritius and can be challenged by English weather! She is qualified as a teacher in yoga and food nutrition.

Michelle Guy PhD: We are delighted to announce the birth of Elsa Grace Dalby on Friday, 17th of December at 2.55pm, weighing 9lbs 2oz. A mere 14 days overdue, Elsa kept us all waiting and beat the sweepstake! She is obviously going to be a winner. Congratulations to Michelle, husband Andy and sister Aimee, who was the star of our last Newsletter.

Tokhir Dadaev MSc – Scientific Officer
From Tashkent in Uzbekistan, Tokhir studied at City University London in Business Systems Analysis and Design. He worked as a lead Information Analyst/Developer for the NHS Information Centre before joining UKGPCS, as a Scientific Officer in November 2010.

When not entertaining his 6 month old son, Theo, he plays table tennis, volleyball and jogs; enjoys architecture and reading; is seriously addicted to online FPS games and has a passion for relational algebraic calculi databases!!

Sarah Keating BSc – Locum Data Manager
Sarah qualified as a Physiotherapist at University of Birmingham in 2010. She took up the post of Locum Data Manager, when Lynne O’Brien left. A keen Korfball and Netball player, Sarah was born in Connecticut USA and wants to live the dream — to be an exceptional interim Database Manager and Physiotherapist.

Rosemary Wilkinson: Sarah will be working closely with Rosemary, our other Data Manager, who is extremely experienced and has been with us for 6 years.

Lynne O’Brien PhD: We bade a sad farewell to Lynne in December 2010 after 7 years with UKGPCS and, 3 years with Cancer Genetics prior to that. She studied Genetics at Liverpool University before completing a PhD at the Royal Free Hospital, as a molecular biologist. Returning to work P/T after having a family, she managed the UKGPCS data systems, trained staff and gave talks to local NCRN Nurses. Creative, exuberant and unforgettable - especially for her cake-making, which she is now pursuing professionally.

Emma Sawyer – Administrator

Emma has returned from Maternity Leave at the end of February 2011, having given birth to her 2nd son, Matthew, on the 9th of June 2010. Emma, husband Chris and 3 year old brother, Jacob, are enjoying their new family.

Romayne McMahon: Provides admin. support for the UKGPCS and IMPACT teams. She was born in Goa and has Irish ancestry. She is AAT qualified (Association of Accounting Technicians).

Alison Thwaites: Provides admin. support for the UKGPCS and works for Professor Eeles in the Department of Cancer Genetics. She has 2 young children and talent - plays the flute and tennis.

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