



Don't Forget Prevention

One 400 microgram tablet of folic acid taken every day by all women who are capable of becoming pregnant will prevent many cases of neural tube defects. Folic acid may also help prevent miscarriages.

Race of Brave Bikers

On the 28th/29th of April 2013, a cycle event for survivors of cancer during childhood and adolescence took place in Marostica, near Venice, in Northern Italy.



The event, named 'The Race of Brave Bikers', is now in its second year and is sponsored by PanCareSurFup.

Funding (cycling gear, see photo, as well as bicycles, travel and expenses) was provided by NEAR Foundation, Barilla Food Group, and run in association with the professional bicycle race – GranFondo Fisik.

The event saw a group of young cancer survivors from across Europe and their supporters line up together and undertake a special 10K route through the ancient town of Marostica, Vicenza, Italy.



The cycling event was held as part of PanCareSurFup's dissemination activities to raise awareness of the increasing number of paediatric cancer survivors in Europe. The event demonstrates the importance of optimum quality-of-life for the survivors and the need for research studies into the late effects of their complex paediatric cancer treatment.

Annual Reports

Annual reports of the Boyne Research Institute are available at: <http://www.boyneresearch.ie/annual-reports.html>

Cruise Toward Life

PanCare and PanCareSurFup were delighted to be part of the fundraising event - "Cruise toward Life" which was held in Genoa, Italy on 24th/25th October 2013. The event was run by MSC Cruises with the support of other Italian sponsors.

The aim was to inform people not directly involved in childhood cancer about the success in Europe of treating children and adolescents affected by cancer, the importance of the cooperative work of a European group like PanCare, and the goal of achieving a complete cure in childhood cancer, which is today a reality, as well as the task of caring about the health status of long-term survivors (role of PanCareSurFup).



Dr Byrne attended the evening aboard MSC Opera which included a cocktail reception, dinner, speeches, entertainment and an auction. The evening was a great success with 1,200 guests in attendance. Boyne Research Institute was involved in producing a banner and postcard for the event to raise awareness of PanCare.



A press conference and round table was arranged for the following day. It involved scientific experts from Italy (AIEOP), Europe (PanCare), and the U.S., who discussed results, problems, and projects on childhood cancer.

Thank You

We thank Ita Deveney, and the Sequoias Ladies Golfing Society of Armagh, Northern Ireland for their generous donation to the Boyne Research Institute. We are very grateful to all our donors for their support of our Summer Student Programme 2014.

Mission The Boyne Research Institute is a community-based research facility that conducts research directed towards a better understanding of the origins and prevention of birth defects and the long term consequences of cancer during childhood. www.boyneresearch.ie

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Late effects studies

BRI's involvement in European late effects studies and care dates back to our membership in the ELTEC Committee of the International BFM Study Group of leukemia/lymphoma in children. ELTEC begat PanCare and Dr. Byrne is a founding member. Treatment for childhood cancer has improved greatly in the last 60 years, and now approximately 80% of children will reach the 5-year survival point, most being considered cured of their original disease. However, the therapies that produced cures are toxic to healthy tissues, and can have long-term complications, especially in a growing child. This new group of patients is increasing; estimates suggest that Europe has between 300,000 and 500,000 survivors of childhood cancer. Not all require long-term care, but some do, and at different levels of surveillance. These issues are of concern to the late effects community of PanCare.



PanCare

Founded in Lund, Sweden, in 2007, PanCare is a multidisciplinary pan-European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer. The long-term strategic aim of PanCare is to ensure that every European survivor of childhood and adolescent cancer receives optimal long-term care. PanCare has given rise to two pan-European consortia – PanCareSurFup and PanCareLIFE – to implement this strategy.

www.pancare.eu

PanCareSurFup



PanCareSurFup is a €6 million EU-funded, 5 year project that started in 2011. It evaluates the risks from cancer treatment on the long-term health of cured survivors of cancer diagnosed during childhood or adolescence. Fifteen institutions from 10 European countries are in the process of pooling data concerning the risk of second cancer, of secondary cardiac disease, and of late mortality (more than 5 years from diagnosis) in about 80,000 survivors of childhood and adolescent cancer. Now past the half-way mark, the PCSF participants are actively engaged in data acquisition and planning the first publications. The guidelines group has joined forces with colleagues from the US and Canada to create harmonized guidelines for follow-up care based on the best global information to help provide every European survivor with better access to care and better long-term health. The Boyne Research Institute is actively engaged in PCSF with dissemination of methods and results, communication with stakeholders and reviews of procedures.

www.pancaresurfup.eu

PanCareLIFE



PanCareLIFE is a €6 million EU-funded, five-year project that started in November 2013, to investigate three serious late effects, namely, loss of fertility, loss of hearing and impaired quality of life. A group of 15 institutions from 8 European countries will collect data from more than 12,000 survivors to evaluate the risks to their long-term health, to develop guidelines for care, and to disseminate results to the general public. This innovative project will look at the ways that genetic make-up can modify risks of late effects. Stratifying survivors into different risk groups so that long-term care can be delivered more efficiently will save survivors and the health-care system time, worry and money. The Boyne Research Institute serves as Research Manager for the PanCareLIFE consortium and looks forward to our active engagement in all aspects of this project.

www.pancarelife.eu



Kick-off Meeting, Mainz, Germany 11th -13th November 2013

BRI Publications

Irish Families with Neural Tube Defects: a long-term investigation into the epidemiological and molecular factors that are linked to the occurrence of neural tube defects.

- Green RF, Byrne J, Crider KS, Gallagher M, Koontz D, Berry RJ. Folate-related gene variants in Irish families affected by neural tube defects. *Frontiers in Genetics* (2013) 10.3389/fgene.2013.00223

With our colleagues from CDC Atlanta, USA, we examined 5 gene variants involved with the metabolism of folic acid in 322 members of Irish families. In line with our earlier results we found that, compared to paternal relatives, maternal relatives had a higher number of gene variants linked to lower folate metabolism. This suggests an epigenetic mode of inheritance for NTDs.

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