

Survivorship Conference, November 2011

As part of the Boyne Research Institute's participation in the PanCareSurFup consortium (see below), we are organising, in association with the Irish Cancer Society, the first Irish Conference on Survivorship after Cancer in Childhood and Adolescence. The Conference will take place in the Croke Park Conference Centre on 26th November 2011. Co-sponsors are the European Union and its 7th Framework Programme (FP7). Other co-sponsors include the Children's Medical & Research Foundation of Crumlin Children's Hospital in Dublin and Novartis, a pharmaceutical company. The programme includes a lineup of national and international speakers on topics that are important for survivors, such as second malignancies and cardiac disease. Other speakers will address quality of life issues, and follow-up in Ireland. Please visit www.ccs2011.ie

The purpose of the conference is to raise awareness around survivorship after childhood cancer, and to address issues of importance to survivors, including policy changes.

European Networks Studying Late Effects after Cancer in Childhood and Adolescence

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. Most European countries are represented. PanCare is working to achieve equity of access to care for childhood cancer survivors across Europe, to perform collaborative research and to act as a resource of research based information concerning all late side-effects of cancer treatment. An important aim of PanCare is to work with the European Community to increase awareness and research about childhood cancer survivors. 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 was founded at a meeting in March 2008 in Lund, Sweden. The Boyne Research Institute is represented on the Interim Board and other committees of PanCare. (www.pancare.eu). Currently, PanCare's major research project is the PanCareSurFup consortium, described next. PanCare also has working groups focusing on fertility, on quality of life and on ototoxicity (hearing impairment).

2011 Summer Student Programme, July-

August.

Each year the Boyne Research Institute offers a summer training programme to two Leaving Cert students in



Drogheda-area schools. Following an application and interview, two students are selected (usually one male and one female). Their work includes helping with our research projects, including data entry, and completing their own research project. Each student identifies a different topic, carries out the research, and prepares a formal

Powerpoint presentation. They present their work at a reception for an invited audience, including the Mayor of Drogheda and board members. This year the reception will be on 4th August.

* Aidan Kelly (left) says: "I attended Drogheda Grammar School, and completed Leaving Cert. in June. My work at the Boyne Research Institute includes researching the effects of cancer treatment in children. I have found the work here very interesting. When not researching, you will most likely find me at sea, either sailing or clinging on to a capsized boat".

* Caoimhe McQuillan (right) says: "I was a student at Our Lady's College, Greenhills. The work at the Boyne Research Institute is very interesting and useful. I am researching stomach cancer for my project. In my spare time I love to play the drums and Gaelic football".

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

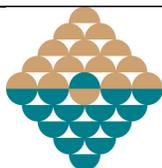
2011 Staff of the Boyne Research Institute

Rebecca Lawler, administrator/researcher.

Julianne Byrne, director of the Boyne Research Institute is an epidemiologist.

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Recommendation

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, and probably also miscarriages.

PanCareSurFup is a consortium funded by the 7th Framework Programme of the EU (FP7) to carry out a series of research projects, to develop guidelines for long-term follow-up based on the research results, and to disseminate the results as widely as possible (www.pancaresurfup.eu). The research projects concern 1) estimating the dose of radiation to different parts of the body received by children as part of their cancer treatment; 2) estimating the risk of second malignancies to children who have had a first cancer; 3) developing risk estimates for heart disease following treatment and 4) determining the risk of late mortality in long-term survivors. Results from PanCareSurFup will help to provide every European childhood cancer survivor with better access to care and lead to improved long-term health. The Boyne Research Institute is a participant in this 5-year project, still in its first year. We have responsibilities in each of the above research projects, but our biggest piece of work is in dissemination. To fulfill this responsibility we are organizing the first Irish Conference on Survivorship after Cancer in Childhood and Adolescence in November 2011. PanCareSurFup will sponsor other conferences on this theme over the 5-year course of this project.

Genotyping study

In 2007, many relatives in our study, Irish Families with Neural Tube Defects, participated in a new study that involved giving a blood sample. In order to evaluate the role of an underlying genetic predisposition to birth defects, we formed a collaboration with the Centers for Disease Control and Prevention in Atlanta, Georgia, USA, part of the federal government. In 2008 the lab in Atlanta analysed ('genotyped') the blood samples for the presence of variants in five genes. The five genes have been intensively studied by others, since they are part of the way that the body processes folic acid coming in the diet. We looked at whether different gene variants might occur more commonly in some relatives rather than in others. Specifically we were interested in whether some occurred more often among maternal relatives than among paternal relatives. Our studies have shown consistently that maternal relatives in the group of families we study are more likely to have birth defects, including neural tube defects. When we finished the analyses of data, we could show that our hypothesis was supported, that is, maternal relatives are more likely than paternal relatives to carry some types of gene variants. This provides evidence that the patterns we have been seeing are based in genetic mechanisms. Females related through

the mother in NTD families still need to be taking extra folic acid (folic acid supplements), since they have that extra risk. These results are being prepared for publication.

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

Publications, 2010-11

Byrne J. Birth defects among maternal first cousins in Irish families with neural tube defects. *Irish Journal of Medical Science*. 2010 Sep;179(3):375-80.

**Maternal first cousins have a increased risk of having a birth defect, overall, compared to paternal first cousins.*

Green D, Kawashima T, Stovall M, Leisenring W, Sklar C, Mertens AC, Donaldson AD, Byrne J, Robison LL. Fertility of male survivors of childhood cancer. A report from the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*. 2010 Jan 10;28(2):332-9.

**Male survivors who were not surgically sterile were only half as likely to become fathers compared to siblings.*

Cruz, Maria Leticia Santos, Laura Freimanis Hance, James Korelitz, Maria Cervi, Adriana Aguilar, Julianne Byrne, Leslie K Serchuck, Rohan Hazra, Carol Worrell for the NISDI Pediatric Study Group. *Journal of Tropical Pediatrics*, 2011; 57 (3): 165-172.

**Data from 120 Latin-American youth showed inadequate levels of virologic suppression despite antiviral treatment.*

Byrne J. Three generations of matrilineal excess of birth defects in Irish families with neural tube defects. *Irish Journal of Medical Science* (2011) 180:69-72.

**Maternal first cousins once removed were the third generation in this group of Irish families to have more birth defects in maternal relatives than paternal relatives.*

Byrne J. Periconceptual folic acid prevents miscarriage in Irish families with neural tube defects. *Irish Journal of Medical Science*, (2011) 180:59-62.

**Folic acid taken during pregnancy reduced the rate of miscarriages by almost 60% in pregnancies to Irish families with neural tube defects.*

Byrne J, Horan J, Nicholson HS. *Acute toxicities, late sequelae, and quality of survivorship in children with acute myeloid leukemia: The impact of allogeneic stem cell transplant*. In GH Reaman & FO Smith (eds). **Childhood leukemia**. Springer-Verlag Berlin 2011.

**A book chapter describing the long-term consequences of allogeneic bone marrow transplant after acute myeloid leukemia.*

Copies are available by emailing admin@boyneresearch.ie

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