

Boyne Research Institute

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## Annual Report 2011

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Boyne Research Institute

## *Annual Report, 2011*

**Mission** The joint missions of the Boyne Research Institute comprise research and education. Our research mission is to help understand the causes and consequences of diseases during childhood. Our current projects include studies into the causes of birth defects in families, and the long-term complications of cancer during childhood. Our educational mandate is to provide research experiences for young people from the community, and training for junior scientists.

**Objective** While retaining our present structure of independence and our community base, we are committed to becoming a world-class research institute. We aim to achieve this by expanding partnerships to complement our capabilities.

**Goals for the Next Five Years** Development of BRI's capacity to carry out joint epidemiologic-molecular projects with our research partners is a major part of our vision for the next five years. We also aim to expand our student training programmes to include more third-level and post-graduate students from Ireland and from overseas. Expanding our sources of research and training funds is a major prerequisite for these goals.

**Websites** For more information on the research approach, newsletters, publications, presentations and results of our studies please visit [www.boyneresearch.ie](http://www.boyneresearch.ie). Presentations, photographs and reports from the Survivorship Conference are at [www.ccs2011.ie](http://www.ccs2011.ie). Activities concerning childhood cancer survivors in 2012 will appear on the website [www.ccs2012.ie](http://www.ccs2012.ie).

You can also obtain reprints and reports of our studies from [admin@boyneresearch.ie](mailto:admin@boyneresearch.ie).

### **From the Director**

*In 2011 the work of the Boyne Research Institute continued into its 19<sup>th</sup> year. We are grateful to all those who provided support in many different ways during these years. This year we had a successful Summer Student Programme, welcomed our first marketing and events manager and welcome volunteers.*

*Our work with Irish Families with Neural Tube Defects brings its epidemiologic aspects to a close with the publication of the final results from interviews with three generations in the participating families. The next steps involve reports on associations with specific gene variants.*

*Our European collaborations continue to grow and bear fruit. PanCare had two successful meetings. PanCareSurFup sponsored the first Irish Conference on Survivorship in November. A bicycle race in Italy for survivors is planned for May 2012. More pan-European studies involving BRI and PanCare are in the pipeline.*

*I am grateful to the staff, volunteers and board members for their support and good will throughout the year. Support from the local community and from friends and foundations in the United States continues to be crucial. Many blessings on you all.*

Julianne Byrne, Director



## SUMMARY OF RESEARCH RESULTS FOR 2011

### 1. STUDIES INTO THE GENETIC ORIGINS OF NEURAL TUBE DEFECTS

**Project Title:** Irish Families with Neural Tube Defects

**Overall Objective:** To uncover evidence of inheritance patterns within families where an individual has been born with a neural tube defect (NTD). Markers of inheritance patterns with underlying genetic susceptibility are birth defects and adverse pregnancy outcomes (miscarriages, stillbirths and preterm deliveries).

**Methods:** Between 1995 and 2002, 79 Irish families with NTDs participated in this research project of the Boyne Research Institute in Drogheda. The first phase consisted of an interview with the nuclear family (parents), covering the health of the proband and family members, including a reproductive history. In subsequent phases we interviewed uncles and aunts, first cousins, the proband and siblings. In 2007, BRI carried out a study of folate status among 325 relatives (of all types) in these families. Molecular genetic analysis of 5 single nucleotide polymorphisms was done in 2008 in collaboration with CDC in Atlanta.

**Results:** Maternal relatives in these families have more birth defects overall, including more NTDs, than paternal relatives, and than expected based on the general public. This tendency is present in three consecutive generations (uncles/aunts, first cousins and first cousins once removed), without any suggestion of attenuation.

In addition, pregnancies to first cousins were less likely to end in miscarriage if the mother took supplemental folic acid tablets before or during early pregnancy (Figure 2). That folic acid helps prevent birth defects, including neural tube defects, has been accepted for some time. Our study of first cousin pregnancies also showed a reduction of birth defects in women who took folic acid as recommended. But the extra benefit of folic acid in reducing miscarriage rates is not as widely known.

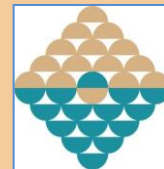
#### CONCLUSIONS

This pattern of preferential maternal inheritance has been reported in many previous studies for neural tube defects alone, and for the first time by the Boyne Research Institute for birth defects overall. In addition, our studies show persistence of this pattern through three generations of the same families. The pattern suggests that some factor is travelling along the maternal line that brings extra risk of birth defects. The factor may be genetic, that is, linked to genes and DNA, or it may be some other alteration in the cell. We are currently investigating these possibilities. The implications for public health are clear: family members, especially those related through the mother, really should be taking folic acid as recommended. (*Publication details in References*)

### 2. LATE EFFECTS AFTER CHILDHOOD CANCER

**Overall Objective:** The objective of this project is to initiate and carry out research studies into the long-term consequences of cancer during childhood to survivors and their families in a European context, and related focused research investigations.

**Background:** Survival after childhood cancer approaches 80% in developed countries. The long-term consequences of cancer and its treatment include second cancers, deficits in fertility and cognitive functioning for some, but not all survivors. As treatments evolve and improve, continued follow-up of existing and new cohorts of survivors is needed to provide accurate and timely information for survivors to prevent and remediate where possible the long-term consequences of cancer and its treatment.



### 2011 Activities

1. **Survival after childhood cancer in Ireland:** BRI collaborated with staff from the National Cancer Registry of Ireland to evaluate the level of survival after cancer during childhood in Ireland, and to see if any disparities in relation to area of residence or socio-economic status could be detected. Approximately 120 new cases of cancer occur in Irish children before 15 years of age. The overall five-year survival rate at 79% is close to European rates for more developed countries. No evidence for disparities in survival related either to region or socio-economic status could be detected. Published in the *European Journal of Cancer*, 2011.
2. **Late Effects after Bone Marrow Transplant for Acute Myeloid Leukemia in Childhood:** Dr. Byrne was first author of a chapter in a new publication, entitled *Childhood Leukemia*, edited by GR Reaman and FO Smith, published by Springer-Verlag in 2011. The full title of the chapter is "Acute Toxicities, Late Sequelae, and Quality of Survivorship in Children with Acute Myeloid Leukemia: The Impact of Allogeneic Stem Cell Transplant".
3. **PanCare:** The Boyne Research Institute is a founder member of PanCare, a Pan European consortium for research and care of survivors of cancer during childhood and adolescence ([www.pancare.eu](http://www.pancare.eu)). Dr. Byrne is a member of the board. The Boyne Research Institute holds the office of Treasurer pro tem.
4. **PanCareSurFup (PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies, [www.pancaresurfup.eu](http://www.pancaresurfup.eu)).** The Boyne Research Institute is a participant in this 16-member consortium from 11 European countries, that runs for 5 years from 1 February 2011 to 31 January 2016, funded by the European Union's 7<sup>th</sup> Framework Programme (FP7). Dr. Byrne is Research Liaison in this consortium. The Boyne Research Institute is represented in all 8 work packages of PanCareSurFup; Dr. Byrne is the deputy leader of WP7, which is the dissemination and training work package. The main activity of WP7 in 2011 was the organization of the first Irish Conference on Survivorship after Cancer during Childhood and Adolescence, in the Croke Park Conference Centre, 26 November. The conference report follows.

#### IRELAND'S FIRST CONFERENCE FOR SURVIVORS OF CANCER DURING CHILDHOOD AND ADOLESCENCE

##### Childhood Cancer Survivors Should Not Smoke at Any Time in Their Lives

SURVIVORS of childhood cancers should not smoke at any time in their lives due to their increased risk of developing second cancers, Nessa Childers MEP has told Europe's first conference on childhood cancer survivorship, which was held in Dublin.

A recent study has shown that one in five childhood and adolescent cancer survivors currently smokes.

Ms Childers, a member of the EU's Committee on Public Health, was addressing the first Conference on Survivorship after Cancer during Childhood and Adolescence on Saturday November 26 at the Croke Park Conference Centre. This is the first European conference for survivors of childhood and adolescent cancers and their families. "Although 80% of survivors will go on to lead fulfilling lives, they will be at increased risk of second cancers, heart disease and other health problems," said Ms Childers. "Given the long-acknowledged carcinogenic effects of tobacco, the message coming from health professionals, patient groups and legislators must be simple – 'if you are a cancer survivor, do not smoke'."

Dr Julianne Byrne, founder of Boyne Research Institute, Drogheda and organiser of the inaugural conference for young cancer survivors and their families, endorsed Ms Childers' message. "Children who have had cancer should be encouraged to not even think about smoking for the first time," said Dr Byrne. The slides shown by the speakers are available in pdf format

Dr Lars Hjorth of the University of Lund in Sweden told the conference that childhood cancers have become more curable, with five-year survival in Europe rising from 44% in the 1970s to 74% at present. In Ireland, nearly 80% of children diagnosed with cancer will live at least five years. Dr Elvira van Dalen of the Emma Children's Hospital in Amsterdam described the excess risk for heart disease at a young age that childhood cancer survivors face, and pointed out that smoking is an added and avoidable risk for survivors. Although many children will be cured of their original cancer, some may experience long-term complications or late effects as a result of the treatments which can damage many organ systems, she said.

The conference was organised by the Boyne Research Institute in association with the PanCareSurFup consortium and the Irish Cancer Society. PanCareSurFup is a five-year pan-European project funded by the EU's 7<sup>th</sup> Framework Programme. It is investigating the late effects of treatment for cancer during childhood and adolescence, and will establish guidelines for follow-up, disseminate the results and provide training and workshops for stakeholders. The Boyne Research Institute is a partner in PanCareSurFup. The consortium hopes to hold similar conferences in other European countries.

Speakers were drawn from the UK, Holland, Sweden, Italy and Germany, and included experts in epidemiology, cancer registries, paediatric oncology, and patient and Irish parent advocate organisations, such as Barretstown, CanTeen and Hand-in-Hand. For presentations & photos, visit [www.ccs2011.ie](http://www.ccs2011.ie).



## SUMMER STUDENT PROGRAMME

In 2011 the Boyne Research Institute offered placements in our summer training programme to two Leaving Certificate students from Drogheda-area schools, following an application and interview process. Summer Students' work includes helping with BRI 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. Their work was presented at a reception for an invited audience, including the Mayor of Drogheda and BRI board members on 28 August 2011.

\* Aidan Kelly 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 says: "I was a student at Our Lady's College, Greenhills. The work at the Boyne Research Institute is very interesting - learning about stomach cancer for my project, learning touch typing, mail merges and how to prepare and integrate references into a scientific manuscript".



## STAFF & VOLUNTEERS

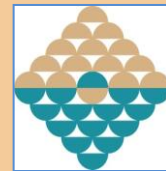
Staff in 2011 consisted of director, Dr. Julianne Byrne, assisted by research administrator Rebecca Lawler. Rosaire Kelly joined us as a volunteer and contributed significantly to the success of the Survivorship Conference. She continues to work on publicity issues for the Institute. Ciara Hall came to the Boyne Research Institute in July 2011 as marketing manager and events coordinator, with primary responsibility for organizing the very successful Survivorship Conference.



L. to R.: Rosaire Kelly, Ciara Hall, Rebecca Lawler, Mayor of Drogheda Kevin Callan, Aidan Kelly, Caoimhe McQuillan, Julianne Byrne

## MEETINGS & PRESENTATIONS

1. **PanCare** Meetings in 2011: Spring meeting in Brno, Czech Republic, 27-29 April; Autumn meeting in Amsterdam, 1 October.
2. **PanCareSurFup**: Spring meeting in Brno, Czech Republic, 26 April; Autumn meeting in Amsterdam, 2 October.
3. **ESLCCC2011**, European Symposium on Late Complications after Childhood Cancer, 29-30 September, Amsterdam: Dr. Byrne co-chaired a symposium entitled: *Research in childhood cancer survivors*. Dr. Byrne also presented a poster entitled *Childhood cancer survival in Ireland: temporal, regional and deprivation-related patterns*
4. **NICR**, Third National Conference on Population-Based Cancer Research in Ireland: Dr. Byrne presented a poster entitled: *Childhood cancer survival in Ireland: temporal, regional and deprivation-related patterns*



## COLLABORATIONS

For a number of years, the Boyne Research Institute has participated in national and international collaborations, in areas covering developmental problems resulting in birth defects and cancer during childhood. At present, we are involved in collaborative research with research teams in Europe and the United States of America.

- ❖ Dr Paul Walsh, Dr. Harry Comber, National Cancer Registry of Ireland, Cork, Ireland
- ❖ Dr RJ Berry, National Center on Birth Defects & Developmental Disabilities, Centers for Disease Control & Prevention, Atlanta, GA, USA,
- ❖ Dr. Lars Hjorth, University of Lund, Sweden (chairman, PanCare & coordinator, PanCareSurFup)
- ❖ Dr. James Korelitz, Westat, Rockville, MD, USA.

## GOVERNANCE OF THE BOYNE RESEARCH INSTITUTE, 2011

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### BOARD OF TRUSTEES

Dr. Carlos McDowell (Chairperson)  
 Mr. Gerry Fitzgerald (Secretary)  
 Mr. Patrick Morris  
 Dr. Julianne Byrne

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We are grateful to those members of our Board of Trustees who give freely of their time and energy to help advance the mission of the Boyne Research Institute. The Board of Trustees meets quarterly.

## PUBLICATIONS, 2011

1. 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 2009*. Journal of Tropical Pediatrics, 2011; 57 (3): 165-172.
2. 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.
3. Byrne J. Periconceptional folic acid prevents miscarriage in Irish families with neural tube defects. Irish Journal of Medical Science, (2011) 180:59–62.
4. 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.
5. Walsh PM, Byrne J, Capra M, Comber M. Childhood cancer survival in Ireland: temporal, regional and deprivation-related patterns. European Journal of Cancer (2011) 47(12):1852-1862. <http://dx.doi.org/10.1016/j.ejca.2011.03.021>

## ABSTRACTS PRESENTED AT SCIENTIFIC MEETINGS, 2011

1. Byrne J, Walsh P, Capra M, Comber H. *Childhood cancer survival in Ireland: temporal, regional and deprivation-related patterns*. Poster presentation at ESLCCC2011, European Symposium on Late Complications after Childhood Cancer, Amsterdam, Holland 29-30 September 2011.
2. Walsh P, Byrne J, Capra M, Comber H. *Childhood cancer survival in Ireland: temporal, regional and deprivation-related patterns*. Poster presentation at Third National Conference on Population-Based Cancer Research in Ireland, 17 November 2011, Gresham Hotel, Dublin.