

Boyne Research Institute

Annual Report 2012

Boyne Research Institute
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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 collaborative epidemiologic-molecular projects in birth defects and childhood cancer will help make BRI a centre of excellence for health studies in Ireland.

Websites For more information on the research approach, newsletters, publications, presentations and results of our studies please visit www.boyneresearch.ie. Activities concerning childhood cancer survivors in 2012 will appear on the website www.ccs2012.ie.

Reprints and reports of BRI studies are available from admin@boyneresearch.ie.

From the Director

Now in our 20th year, the work of the Boyne Research Institute continues to grow and change. We are immensely grateful to all who have provided support in many different ways during these years. Once again, in 2012 we had a successful Summer Student Programme, and were able to establish new relationships in Ireland and in Europe that will expand our research collaborations.

Our European collaborations continue to grow and bear fruit. PanCare had two successful meetings in 2012. Our EU consortium, PanCareSurFup, sponsored the first Irish Conference on Survivorship in November, 2011. Our Italian research partner, Dr. Momcilo Jankovic, arranged a bicycle race in Italy for survivors held in May 2012. This event will be recur in April 2013, and for the next four years. 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 2012

1. STUDIES INTO THE GENETIC ORIGINS OF 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). Epidemiologic signs of inheritance patterns with underlying genetic susceptibility are birth defects and adverse pregnancy outcomes (miscarriages, stillbirths and preterm deliveries).

Background: 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 collaboration with CDC in Atlanta. Publications are available at <http://boyneresearch.ie/ntd.html>.

Activities in 2012: A report on the associations between molecular markers and maternal transmission is being prepared for publication.

2. LATE EFFECTS AFTER CHILDHOOD CANCER

Overall Objective: To carry out research studies into the long-term consequences of cancer during childhood to help survivors and their families make informed choices to improve and maintain their health.

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.

2012 Activities

1. **Survival after childhood cancer in Ireland:** BRI developed a website, www.ccs2012.ie, to provide information about childhood cancer survival in Ireland and BRI's collaboration with its European counterparts into the late effects of treatment after cancer during childhood and adolescence. It provides useful links to many support groups in Ireland and Europe, as well as updates on our events and publications.
2. **PanCare** (www.pancare.eu): 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. Dr. Byrne continues as a member of the board. The Boyne Research Institute holds the office of Treasurer pro tem.
3. **PanCareSurFup (PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies, www.pancaresurfup.eu):** The Boyne Research Institute is a participant in this 16-member consortium from 12 European countries. It runs for 5 years from 1 February 2011 to 31 January 2016 funded by the European Union's 7th Framework Programme (FP7). Dr Byrne is Research Liaison in this consortium. Dr. Byrne is the deputy leader of WP7 - the dissemination and training work package, functions as Research Liaison for the consortium and is on the Executive Board. In 2012 WP7 organised the "The Race of Brave Bikers" in Marostica, Italy. BRI helped to advertise the event in Ireland and to choose two Irish participants, Karen O'Neill and Ian Hanrahan (see below for more information).
BRI was also involved in coordinating the translation of the shortened version of the English PanCareSurFup brochure into Italian, French, German, Romanian and Polish. To view these brochures visit our websites at: <http://boyneresearch.ie/pancaresurfup.html> or <http://www.ccs2012.ie/publications.html>.



RACE of BRAVE BIKERS, May 2012



On the 5th/6th May 2012 Dr Byrne, along with two young Irish cancer survivors Ian Hanrahan and Karen O'Neill (*see photo on left*), travelled to Marostica, Italy to take part in a cycle event for survivors of cancer during childhood and adolescence. The event, named 'The Race of Brave Bikers' by its Italian sponsors, saw 30 young cancer survivors from around Europe line up together and undertake a special 10K route through the town of Marostica. The race, which commenced on the start line of the professional cycle race 'Granfondo Fizik', was the high point of a busy weekend. Also included was a roundtable featuring experts and doctors from leading European hospitals, who described their role in the project to stakeholders, including survivors, and promoted the message that every European childhood cancer survivor deserves access to the best possible care and better long-term health. More information and photos are available at: <http://www.ccs2012.ie/events.html>.

BOYNE 10K, May 2012

On 6th May 2012 five runners from Drogheda ran in the Boyne 10k to raise funds for BRI. Rebecca Lawler, our administrator, and her husband Mark, together with Edward McGuirk, Conor Kelly, Caitríona Kelly and Damien Kavanagh all ran in the race. We would like to thank them for their support and we are most grateful to all those who kindly sponsored them.



Left to right: Conor Kelly, Caitríona Kelly, Mark Lawler & Rebecca Lawler

VISITING SCIENTIST PROGRAMME, November 2012

Dr Claire BERGER, a consultant in paediatric oncology/haematology, from Saint-Etienne in France, spent two weeks in Drogheda, from 4th to 17th of November 2012. She chose Drogheda as her base because of her connection with Dr Byrne through PanCare.

Dr Berger is chairperson of the Rhône-Alpes childhood cancer registry and coordinator of the French national late effects committee. She has a keen interest in the late effects of cancer treatment on survivors of cancer during childhood and adolescence. Dr. Berger's current project entitled SALTO: Long-term follow up in oncology will evaluate fertility problems and quality of life in survivors from the Eastern region of France.



Left to right: Dr. Julianne Byrne, Rosaire Kelly, Rebecca Lawler & Dr Claire Berger

Dr Berger also visited the Department of Paediatric Haematology and Oncology in Our Lady's Children's Hospital, Crumlin in Dublin where she assisted in Dr Michael Capra's late effects clinic.



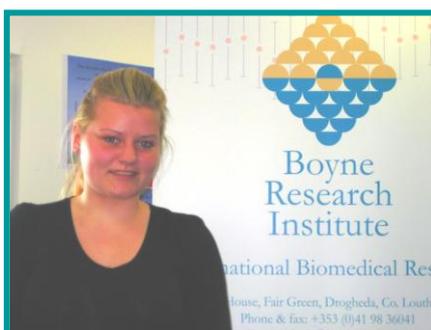
SUMMER STUDENT PROGRAMME 2012



Left to right: Dr. Julianne Byrne, Director, Peter Moloney, Dr. Carlos McDowell, Chairperson of the Board of Trustees and Aurelija Rocyte

In 2012 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. This year we interviewed 17 students and the standard of the applicants was excellent, making our choice difficult. The two students chosen were - Aurelija Rocyte and Peter Moloney, both from St. Oliver's Community School. They followed a structured curriculum which included research methods, statistical analysis, budgeting and presentation skills. They each completed an individual project which they presented at a reception for an invited audience of parents, teachers and board members on 8th August 2012.

* **Peter Moloney** says: "I attended St. Oliver's Community College. I plan to study engineering in UCD in the coming year. The work in the Boyne Research Institute is different from anything I have done before and it has been a steep learning curve. It seems like I am learning new skills and honing old ones on a daily basis. For example, I am learning about statistical analysis, creating presentations and discovering how to use databases. When I'm not at work I like to go to the gym with my friends and playing Gaelic. For my project I am researching 'Radioactivity in the Irish Sea'".



* **Aurelija Rocyte** says: "I am from Lithuania and I came to Ireland with my mother and brother just two years ago. School experience in Ireland was very different from that in Lithuania. It was more practical as I did a lot of experiments in science classes. Also I have never worn a school uniform before. I completed my Leaving Cert in June and in the coming year I plan to study Nanoscience in Trinity College, Dublin. The BRI summer student programme is a great opportunity to improve my presentation, writing and language skills. I got experience on article writing, searching for information and presentation of my research project, 'Cancer Treatment and Side Effects', which will definitely be useful in college".

TONER FAMILY DONATION, December 2012

Brendan Toner, a long-time supporter of the Boyne Research Institute, kindly donated €750 to continue the Institute's work into neural tube defects. Instead of presents at his birthday party, Mr Toner requested that his family and friends make a donation for spina bifida research. Dr Byrne, director of the Boyne Research Institute, expressed her sincere thanks to Mr Toner, his family and friends for their generosity and continued support. The photo shows (L to R) Dr. Byrne, Mr. Toner's sister, Róisín Hughes, and administrator Rebecca Lawler.





STAFF & VOLUNTEERS

Staff in 2012 consisted of the director, Dr. Julianne Byrne, assisted by research administrator Rebecca Lawler. Cíara Hall, our marketing manager and events coordinator, left us in January 2012 and we wish her every success in her new job. Rosaire Kelly continues to provide valuable support for the Boyne Research Institute.

MEETINGS & PRESENTATIONS

1. **PanCare** Meetings in 2012: Spring meeting in Bucharest, Romania, 10-11 May; Autumn meeting in London, 8-9 October.
2. **PanCareSurFup**: Spring meeting in Bucharest, Romania, 12 May; Autumn meeting in London, 4th October.

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 Ireland, 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)

GOVERNANCE OF THE BOYNE RESEARCH INSTITUTE, 2012



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.