

Media Release



Thursday 24 April 2015

Lift off! Sydney Children's Hospital, Randwick launches Balloons & Bubbles for World Primary Immunodeficiency Week

Immunology specialists, patients and families from Sydney Children's Hospital, Randwick (SCH) have joined their international counterparts to celebrate World Primary Immunodeficiency Week, reinforcing their commitment to enhanced diagnosis, treatment and support of young people living with primary immunodeficiency diseases (PID).

Thousands of balloons and bubbles have been launched in over 110 locations worldwide as part of a global initiative to promote community awareness of PID, which affects more than 6 million people. In Australia, an estimated one thousand children are currently being treated for PID.

Professor John Ziegler, Head of Immunology and Allergy Services at SCH, said his team was proud to be part of the Balloons & Bubbles initiative, and supported all efforts to promote the importance of early diagnosis and highlighted the exciting advancements in research and treatment options at SCH.

“The outlook for children with PID has improved dramatically in recent years, and SCH is now a leading centre for identifying genetic causes in patients with immune deficiencies,” said Professor Ziegler. “We are using state of the art genetic testing to identify previous unknown immune deficiency syndromes, which is leading to improved diagnosis and treatment plans for our young patients.”

Primary immune deficiency diseases are serious disorders where inherited defects in the immune system result in an increased susceptibility to infection. There are currently more than 250 primary immune deficiency diseases identified, and they often present in the form of "common" infections, sometimes leading medical professionals to treat the infections while missing the underlying cause.

Professor Ziegler said treatment options have come a long way in recent years – with new measures to attack the disease and make on-going treatment better tolerated.

“We now have greater treatment options available to our patients and we have successfully completed bone marrow transplants from non-related donors, using bone marrow (or cord blood) banks. This significantly increases the chances of finding a suitable donor and having positive outcomes. Methods to safely use partly matched parent as a marrow donor have also improved.”

“For those children dependent on regular infusions of immunoglobulin, we also now have the option of offering weekly injections under the skin, meaning they can avoid the travel, disruption, costs and hospital stays required for monthly intravenous therapy. This is a huge step forward in patient care and certainly makes a significant difference to the quality of life of our patients and their families.”

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“We need to be sure that each patient has the best chance of being diagnosed early and effectively treated. World PID Week is an excellent opportunity to educate the medical community and the wider general public about these disorders and how they can best be detected and managed,” said Professor Ziegler.

“Raising awareness is essential,” agreed Christine Jeffery, Executive Officer of the Immune Deficiencies Foundation Australia (IDFA), proud supporters of the SCH “Balloons and Bubbles” launch.

“Early diagnosis will enable people with a PID to access life-saving and life-enhancing treatments and improve their quality of life. We are pleased to join with *Sydney Children’s Hospital, Randwick* to mark World PID Week and highlight the ongoing need for great community awareness so that together we can support patients and their families living with PIDs.

World PID Week runs from 22 – 29 April 2015, and this year’s key message is: *Test. Diagnose. Treat.*

Sydney Children’s Hospital, Randwick

Each year, Sydney Children’s Hospital, Randwick cares for more than 45,800 seriously ill and injured children from across NSW, Australia and beyond in a family-centred, multidisciplinary, expert environment. Sydney Children’s Hospital, Randwick is one the country’s leading centres in paediatric clinical and research excellence and is part of The Sydney Children’s Hospitals Network (SCHN), the largest network of hospital and services for children in Australia. For more information visit www.schn.health.nsw.gov.au

Immune Deficiencies Foundation Australia (IDFA)

IDFA is a not-for-profit health promotion charity raising awareness and caring for people who have Primary Immune Deficiencies (PIDs). For more information and a range of PID resources visit: www.idfa.org.au

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