

FOUNDATION LOBBIES WORLD HEALTH ORGANISATION



Janet Simons

Kids Foundation in association with the International Patient Organisation for Primary Immunodeficiencies (IPOPI) is calling on the World Health Organisation (WHO) to put immunoglobulin back on its List of Essential Medical Products.

WHO took immunoglobulin off the list in April 2003 and according to Kids' general manager Janet Simons, this action could effect PID patients in third world countries.

"In essence, taking immunoglobulin off the list means that it becomes a non essential medicine and therefore is likely

not to be freely available, especially in those countries where the health systems are poorly funded. While the greatest impact will be felt in third world countries, we are also concerned that WHO is creating a dangerous precedent.

"By de-registering immunoglobulin, WHO conveys the wrong message for first world countries as well as third world countries. Immunoglobulin is still today the only effective treatment for many PID patients and it is critical that it is not downgraded and undervalued by a leading and very powerful world organisation," said Janet.

WHO published the first Model List of Essential Drugs in 1977. This list identified 208 individual drugs that together could provide safe, effective treatment for the majority of communicable and non-communicable diseases. The revised 2002 list contains 325 individual drugs – drugs which WHO argues, provide safe effective treatments for the infectious and chronic diseases which effect the vast majority of the world's population.

NEED TO KNOW!

MERC Two Day Marine Course

- Saturday 8 & Sunday 9 May 2004
12-17 Year Old Patient Members Only
Limited Places –
Register by April 10, 2004

Hilton Brown Swimming Courses

- Auckland (Newmarket Olympic Pools, Mt Roskill, Albany, and Onehunga).
Available to patient members of all ages
Limited Places -
Register by April 10, 2004

Ten Pin Bowling Evening

Everyone Welcome!

- Auckland ; 24th April 2pm, Panmure Super bowl, 525 Ellerslie- Panmure Highway.
- Wellington ; 2nd May 3pm, Poirirua Bowland.

Kids Foundation AGM

Everyone Welcome!

Friday 25 June 2004, 6pm

- Auckland ; Tamaki St Thomas Anglican Church, 368 Kohimarama Road.
- Wellington ; The Johnsonville Community Centre, 3 Frankmore Ave, Johnsonville.

Join the Board and staff for refreshments afterwards.

Children's Film Festival

- April -Wellington and Palmerston North
 - July - Auckland
- Contact support staff for times, venues and free tickets.

ADRENALINE EPIPENS REGISTER

The Kids Foundation strives to provide epipens free to patient members. For those members requiring epipens, the Foundation requests that they register their requirements before their medication is due for replacement to assist Kids to meet demand. To register members should contact their local Foundation support staff.

ST JOHNS MEDICAL SUPPORT PACKAGES

the first to care

Thanks to the Royal Oak Trust, Auckland families faced with chronic health and medical emergencies will receive additional assistance. Funding means a limited number of support packages will be made available to families in greatest need including; family subscriptions to St Johns Supporter Scheme enabling free

emergency ambulance service for a year, medical first aid kits and Health Shuttle vouchers for those with transport problems for non-emergency health appointments in the Auckland Region (hospital or doctor). Applications can be made as for any family grant through Kids support staff.

DID YOU KNOW ST JOHNS.....!

- Is often our first port of call in a medical emergency
- Is largely staffed by volunteers and;
- In 2002, answered a staggering 261,486 111 calls, and was responsible for;
- Transporting 26,765 clients to medical appointments
- Running 456 ambulances (servicing 85% of our population)
- Travelling 12,804,520 kilometres
- Training 80,367 students
- Attending 7,746 events and the St Johns...;
- "Friends of the Emergency Department" spent 1,734 hours in hospitals
- "Caring Callers" spent 53,565 hours telephoning and checking the elderly and;
- Conducted the "Safe Kids" Program for 28,865 participants.

For more information visit www.stjohn.org.nz

FAMILY RESPITE HOLIDAYS FOR AUCKLAND FAMILIES

Families in need of break are advised that there are still a few accommodation packs available for a three night stay at the Hururu Falls Motel in Paihia, Bay of Islands. The accommodation vouchers must be used between April and December 2004 and families interested just need to contact Kids Foundation support staff for further information.

HOSPITAL PARKING VOUCHERS

While the Foundation has had only partial success lobbying for subsidised parking, some wards will issue parking vouchers for allocated zones within the hospital and patients should ask staff in charge for details. Kids is also keen to alleviate the trauma of subsidising parking costs for families already under financial stress and thanks to sponsors, such as the South Auckland Support Trust, has Wilson parking vouchers available through support staff.

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www.pidsnz.co.nz

Contact the Kids Foundation
Support Staff:

Auckland - Carol Hadwin
Wellington & South Island -
Sarah Perry

FREE PHONE 0508 300600

CAUSE CHAMPIONS

KIDS TAKE TO WATER WITH NEW ZEALAND COMMUNITY TRUST



Thanks to the New Zealand Community Trust a number of young members will get additional swimming tuition - learn to have fun in the water and about water safety, and some will participate in a special two day marine and land based activity course.

Foundation Manager Janet Simons says she is delighted with the Trust's support and the opportunity created for young members to get swimming and learn about marine matters.

"We are so lucky to be surrounded by and have easy access to a beautiful coastline and numerous opportunities to participate

in water sports. With access to the water so easy it is important that our young members don't miss out when it comes to heading to the beach and more importantly, that they are skilled and water safety conscious," she said.

The two day marine and land based activity course will be held at the Sir Peter Blake Marine Education and Recreation Centre (MERC) located at the southern end of Long Bay Beach, North Shore, Auckland, on Saturday May 8 and Sunday 9, 2004. It will be open to any patient member between the ages of 12 and 17 years and application forms are available on the Kids Website www.pidsnz.co.nz or from Foundation support staff.

MERC is an outdoor education centre providing full instruction in marine and land based activities, including sailing, kayaking, climbing archery, orienteering, abseiling, snorkelling, problem-solving exercises and canoeing. Participants can get a taste of each activity although there is never any pressure on individuals who do not wish to take part.

For young members who haven't learnt to

swim or just need added coaching to lift their competency to swim 400m with confidence swimming classes will be held at Hilton Brown classes in the Auckland Region (Mt Roskill, Albany, Newmarket and Onehunga). The classes run for four terms. Application forms are available on Kids website www.kidsnz.co.nz or from Foundation support staff on Free Phone 0508 300600.

OTHER CAUSE CHAMPIONS:

THE TRILLIAN TRUST, THE SOUTH AUCKLAND CHARITABLE TRUST, THE CENTURY FOUNDATION, THE ROYAL OAK TRUST, THE LION FOUNDATION, THE ENDEAVOUR TRUST, THE NEW ZEALAND COMMUNITY TRUST, PUB CHARITY INCORPORATED, THE TRINITY FOUNDATION, MT WELLINGTON TRUST, TRUSTHOUSE, COGS, THE SOUTHERN TRUST, THE SUNSHINE SHOP, THE ARA LODGE, THE TINDALL FOUNDATION. WISHLIST SPONSORS.

THE KIDS FOUNDATION WOULD LIKE TO THANK ALL OF THE ABOVE FOR SPONSORSHIP OVER THE LAST FEW MONTHS.

MEDICAL MATTERS

NEW RESEARCH POINTS WAY TO DIAGNOSING & MANAGING PRIMARY IMMUNE DEFICIENCY IN THE 21ST CENTURY

Recent Research – Recommendations and Reports, released January 16, 2004 from the United States on "Applying Public Health Strategies to Primary Immunodeficiency Diseases: A Potential Approach to Genetic Disorders" can now be viewed on the Kids website www.pidsnz.co.nz or hard copies obtained from the Foundation information librarian – Sarah Perry.

Foundation Medical Director, and Vice Chair, Dr Rohan Ameratunga says the research is worth viewing as it tracks progress made on the identification and management of PID. "The material highlights for example, how advances in human genetics and the Human Genome Project will play a central role

in the practice of medicine and public health in the 21st Century. However, it also stresses that the usefulness of advances in clinical practice relies on a raft of factors, such as the effectiveness of genetic tests and services.

"The issues surrounding New Born Screening (NBS) are also covered. The research notes that certain severe PI diseases become apparent early in life, with only a short asymptomatic period after birth. Without an effective intervention, the majority result in irreversible complications and death before the end of the first year of life. It suggests there may be a role for population-based newborn screening (NBS)," said Rohan.

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RESEARCH SUMMARY

Primary immunodeficiency (PID) diseases are a group of primarily single-gene disorders of the immune system. Approximately 100 separate PID diseases have been described, but 20 probably account for 90% of cases. While diverse, PID diseases share the common feature of susceptibility to infection and result in substantial morbidity and shortened life spans. Most important, prompt diagnosis and treatment can now lead to life-saving treatment and result in marked improvements in the quality and length of life for patients.

In November 2001, a workshop was convened by the Centre for Disease Control and Prevention (CDC) in Atlanta, Georgia, America to discuss ways to improve health outcomes among persons with PI. A multidisciplinary panel of persons knowledgeable in PI diseases and public health met to identify and discuss public health strategies that could be applied to PI diseases and possibly for other genetic disorders. A systematic assessment based on the established public health framework was applied to the growing group of PI diseases, whose diverse genetic mutations span multiple components of the immune system but mostly lead to increased incidence and severity of infections.

During the meeting, specialists in clinical immunology, public health, genetics, pediatrics, health communication, and ethics from state and federal agencies, academic centers, professional

organizations, and advocacy foundations discussed the four components of the public health framework as they relate to PI diseases. These four components include:

- 1) Public health assessment (application of traditional public health methods to assess the occurrence and impact of PI diseases on communities);
- 2) Population-based interventions (development, implementation, and evaluation of screening tests administered to newborns and clinical algorithms for early recognition of symptomatic persons to facilitate the earliest possible diagnosis and treatment for PI diseases); and
- 3) Evaluation of screening and diagnostic tools (to ensure their quality and appropriateness for identification of patients with PI diseases); and
- 4) Communication (communication with and information dissemination to health-care providers and the public to facilitate prompt and appropriate diagnosis and intervention).

The working group's deliberations focused on challenges and opportunities, priority research questions, and recommendations for future action for these four components. These recommendations, developed by workshop participants, will be useful to medical and public health professionals who are evaluating methods to increase recognition of PI diseases and other genetic disorders.

OUR PEOPLE

REFLECTIONS ON 2003 CAMPS & CHRISTMAS FESTIVITIES



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www.pidsnz.co.nz

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Photography by Susanna Burton