Primary Immune Deficiency:

A guide for Teachers.

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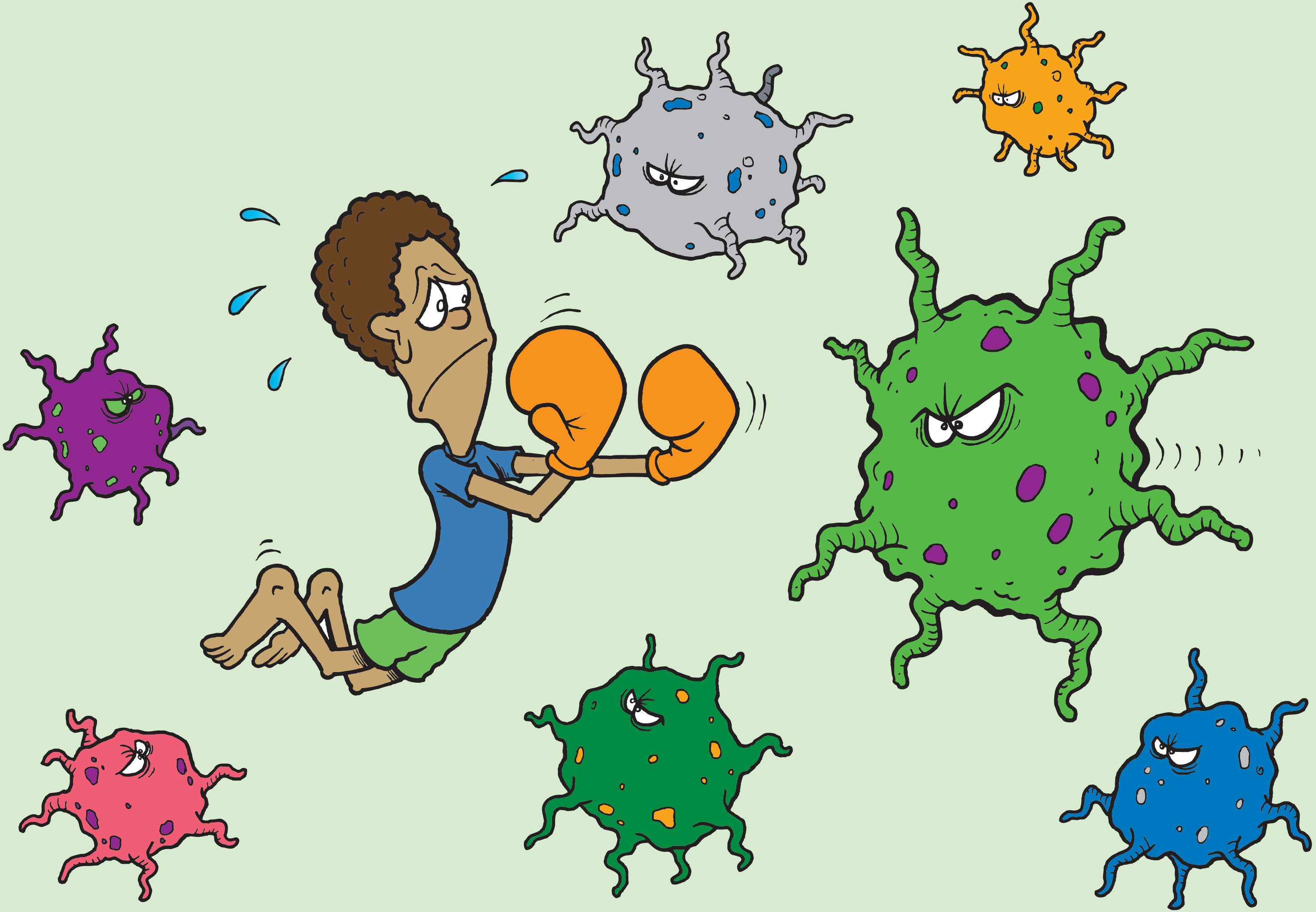
A Guide for Education Staff

This booklet has been produced to help staff working in the education field understand about primary immune deficiency diseases and how they affect children they may work with.
This is not an exhaustive manual as by necessity provides only general information. All questions related to the specific diagnosis should be discussed with the family concerned or your health professional.
The information in this booklet is intended to facilitate communication between teachers, other school staff and the family with a Primary Immune Deficient (PID) child.
As with any chronic illness, appropriate management can minimise the social stressors associated with PID and help each child fulfil their potential across the educational spectrum.



Primary Immune Deficiencies- What are they?

It has been estimated that as many as 1:400 people could have a form of PID. Of these people many will not have any noticeable symptoms. However for many others they live with the constant threat of an infection that they will not be able to fight. PID disorders are where the person's immune system has some part that is not functioning correctly or is absent. These are disorders that a person is born with, caused by a genetic abnormality. They are not "caused" by anything externally, you cannot catch them and they have NOTHING to do with Acquired Immune deficiency (AIDS/HIV).

The World Health Organisation has recognised more than 120 different kinds of PID with the majority being rare or very rare in their occurrence. Untreated they are all characterised by frequent, potentially life threatening infections and ongoing debilitating illness. However with advances in medical understanding of the immune system and the development of effective treatments, it is now possible for many people with PID to live a nearly normal life.

Despite this though, these disorders are chronic and life long and can still cause infections that can impact on daily life in many ways.

Common Treatments and Their side effects

The mainstay for all PID children is antibiotic therapy. Many children will need several courses over the year sometimes remaining on a course for a prolonged time. These courses may need to be administered during school hours so appropriate arrangements may need to be made for this.

The other main therapy used for the majority of PID children is antibody (immunoglobulin) replacement. This is usually given as an intravenous infusion at the local hospital over 4-6 hours. This treatment may give the children some side effects such as headaches, fever, chills and drowsiness. These are all usually very mild but occasionally there might be more severe or serious side effects that will require further time from school.

Some children will have a special intravenous line that stays in permanently called a Central line (Hickman Line) or others may have a special “port” (Porta-Cath) placed under the skin on their chest. Both of these interventions will impact on what the children can or cannot do. Careful consultation with the family will be required to enable a safe activity plan to be drawn up for the individual child.

Prevention is better than cure!

As has been stated all PID children are far more vulnerable to infections than other children. Even with the appropriate medical treatment, infections are always possible. The following are very important areas for all staff to be aware of:

- ANY sign of illness in a PID child should be reported immediately to the school nurse if applicable and to the parent/caregiver as soon as possible.
Signs such as fever, extreme tiredness, pain are indications of possible infection and should always be treated seriously in these children and appropriate medical assistance sought if any serious concern.

- Outbreaks of many communicable diseases can have serious implications for PID children. The main diseases that could cause concern are chicken pox, influenza, glandular fever, meningitis, hepatitis and measles. If any of these conditions occur within the school or kindergarten, the parents should be notified as soon as possible.

- Any open injuries must be attended to immediately. First aid of appropriate cleaning and dressing of the wound should be done by the staff or nurse. Parents need to be informed to ensure that if any further treatment is required it can be followed up at home.

Another area that may cause concern for these children is related to vaccinations. Many PID children cannot produce antibodies in response to the standard vaccinations and so may not have been fully vaccinated. They will also not need further booster shots during their school years. Some children are especially at risk of developing the disease they have been vaccinated with if a live vaccine has been used. In New Zealand commonly used live vaccines include the BCG (for TB), MMR (measles, mumps and rubella) and the chicken pox vaccine. Any vaccination program will need to be fully discussed with the parents.

Special Needs

Each PID child will have their own set of special needs. For many absenteeism will be a constant challenge. Whether it is due to regular treatment, doctor's appointments, illness or hospitalisation for something more serious, children with PID will often miss more school than their classmates. This can be difficult for staff to understand when the child may look quite healthy but they cannot see the subtle changes that show to the parents that their child is not well. If there is concern regarding the number of days that a child has missed from their school year it is important that the family be met with and a plan developed that will help the child met their educational requirements.

The ministry of education has developed an excellent set of guidelines for use within schools when supporting children with chronic health needs. These can be found on their website or via the link:
http://www.minedu.govt.nz/index.cfm?layout=document&documentid=11787&indexid=9921&indexparentid=6871

These documents are a great tool for both parents and staff to use to ensure that communication between all parties is kept at a maximum.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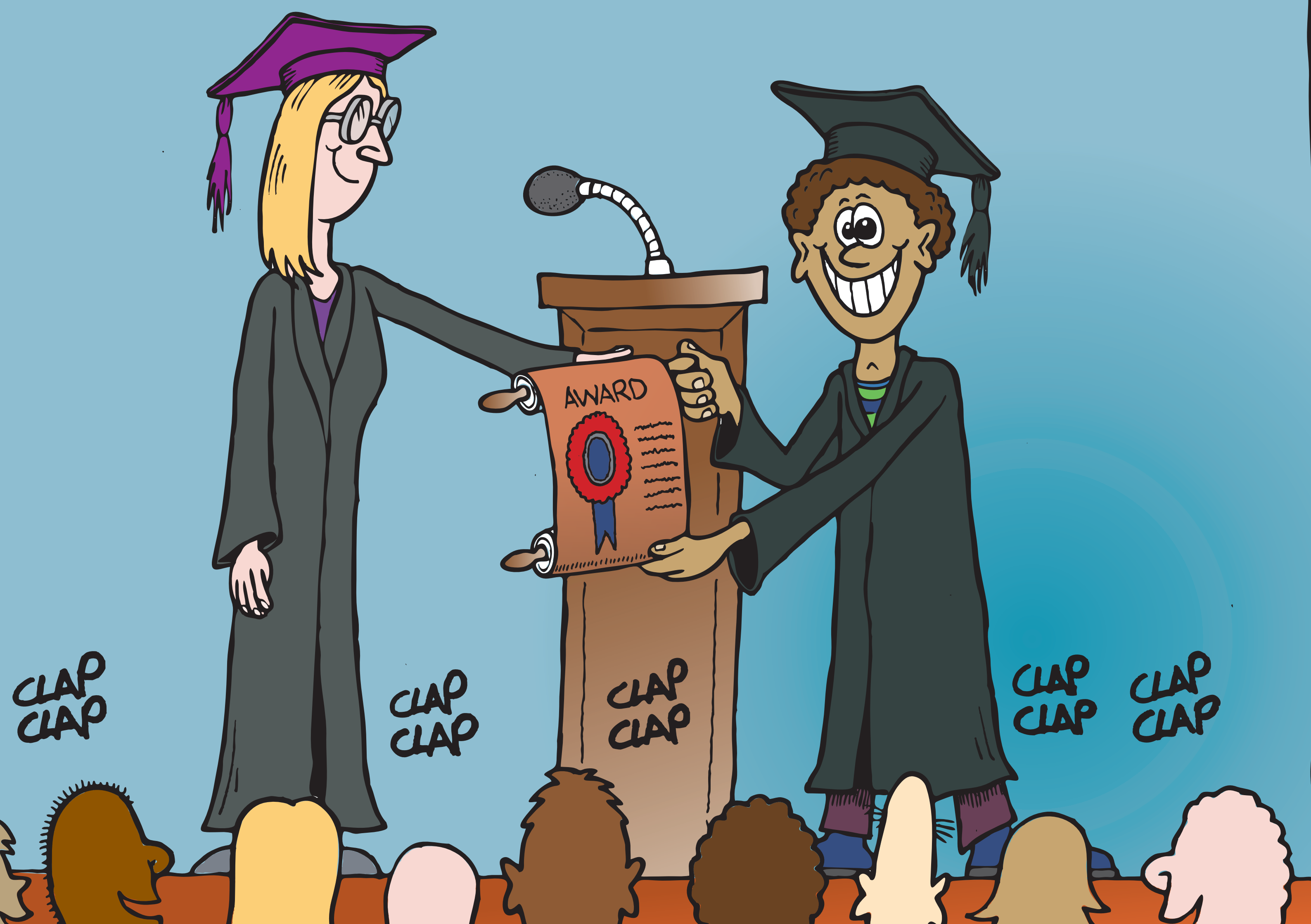
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The future.....

While most immune deficiencies are lifelong conditions with many requiring permanent treatment, with current advances in medical understanding and improvements in treatments the vast majority of these children will grow up into active adults able to participate fully in all aspects of life. What they will need is a little help and understanding along the way to make the most of what life has to offer.

Notes:

The
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key immune deficiency support

The KIDS Foundation is a division of The Immune Deficiencies Foundation of New Zealand Inc. (IDFNZ).
A registered charity supporting Primary Immune Deficient (PID) , Liver and Bowel transplant children across New Zealand.

Further copies of this booklet and other information pamphlets can be purchased / ordered online at www.idfnz.org.nz
Or contact us by post: KIDS Foundation / IDFNZ Registered Charity CC24570

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