



How NMOs can achieve Miracles



*We come from all over the world, different cultures,
different countries, different experiences.
Some of you are “young” NMOs and some of you
(I am sorry to say this...)
are “old” NMOs!
IPOPI is a great place to learn, whether you are
young or old!*

Christine Jeffery
Immune Deficiencies Foundation Australia



What is a “miracle”?



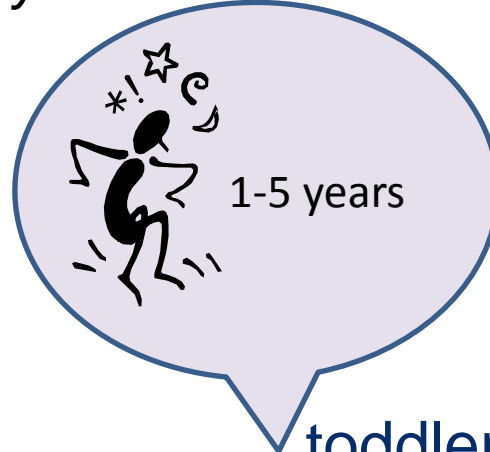
- ☐ *“A remarkable event or development that brings very welcome consequences”*
- ☐ *“An exceptional achievement, or an outstanding example of something”*
- ☐ *“An excellent achievement in a particular area of activity”*



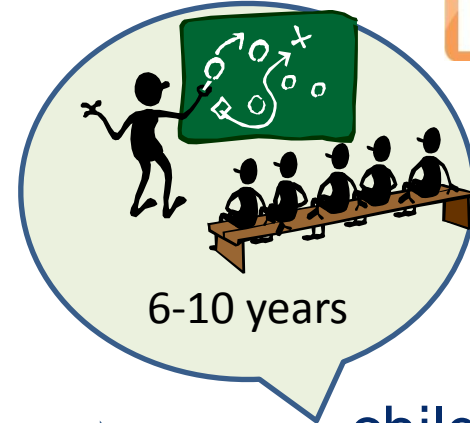
*NMOs have a life cycle – like we do. We have many NMOs represented here at IPOPI. How old is your NMO?
Are you a baby? A child? Young adult?*



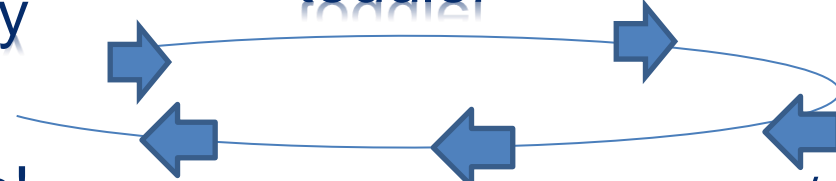
baby



toddler



child



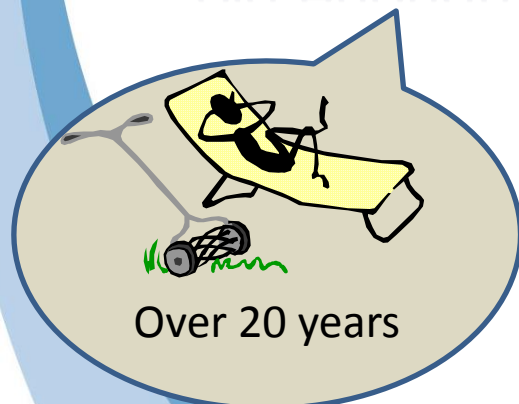
teen / tween



young adult



old enough!





Miracles for parents!



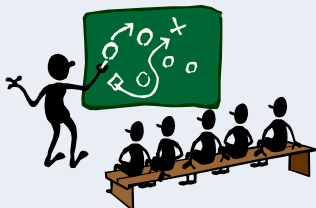
Sleep the night

Need help to do everything
(under 12 months)



No more tantrums

Frustrations trying to establish who you are
(1-5 years)



Love school

Learning about how things work and your place in the world
(6-10 years)



Settle emotions

One minute you have a success, then the next challenge deflates you.
(10-15 years)



Turn down the music!
Get off the phone!

Trying to run your own life and testing the boundaries
(15-20 years)

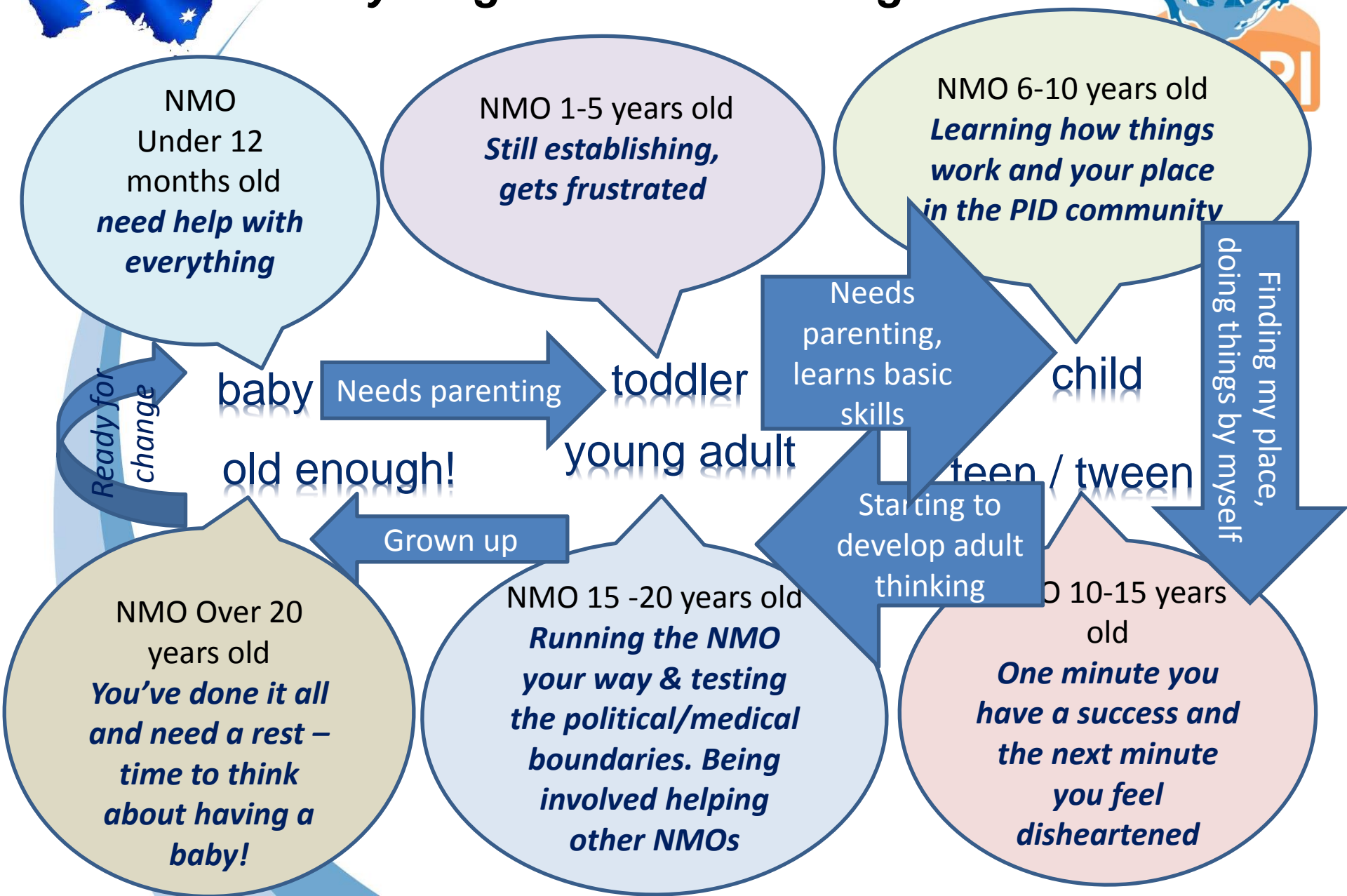


This is the life!

You think you know it all and deserve a little rest
(over 20)



Is your NMO a baby, toddler, child, tween, young adult or old enough?





Can the lifecycle of growing up relate to how an NMO grows?



- Where is your NMO in the Life Cycle?
- If you don't know, what is your age in the Life Cycle?
- Does the age of your NMO reflect the miracles for parents?
- Can you see the connection between parent miracles and NMOs?



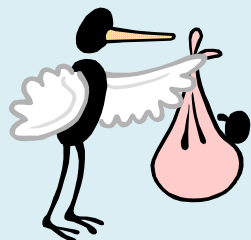
Life cycle:

IDFA was 7 years old
(*a child who had not grown*)
when I became the Executive Officer.

I was “new” (*a baby*).

In the last 2 years I have caught up!

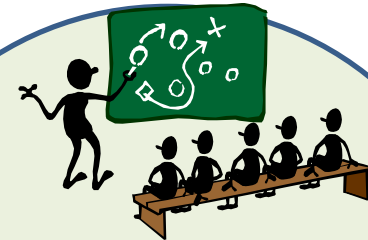
IDFA's position in the NMO lifecycle



Under 12 months
need help with everything



1-5 years
Still establishing, gets frustrated



6-10 years
Learning how things work and your place in the PID community

baby

toddler

teen / tween



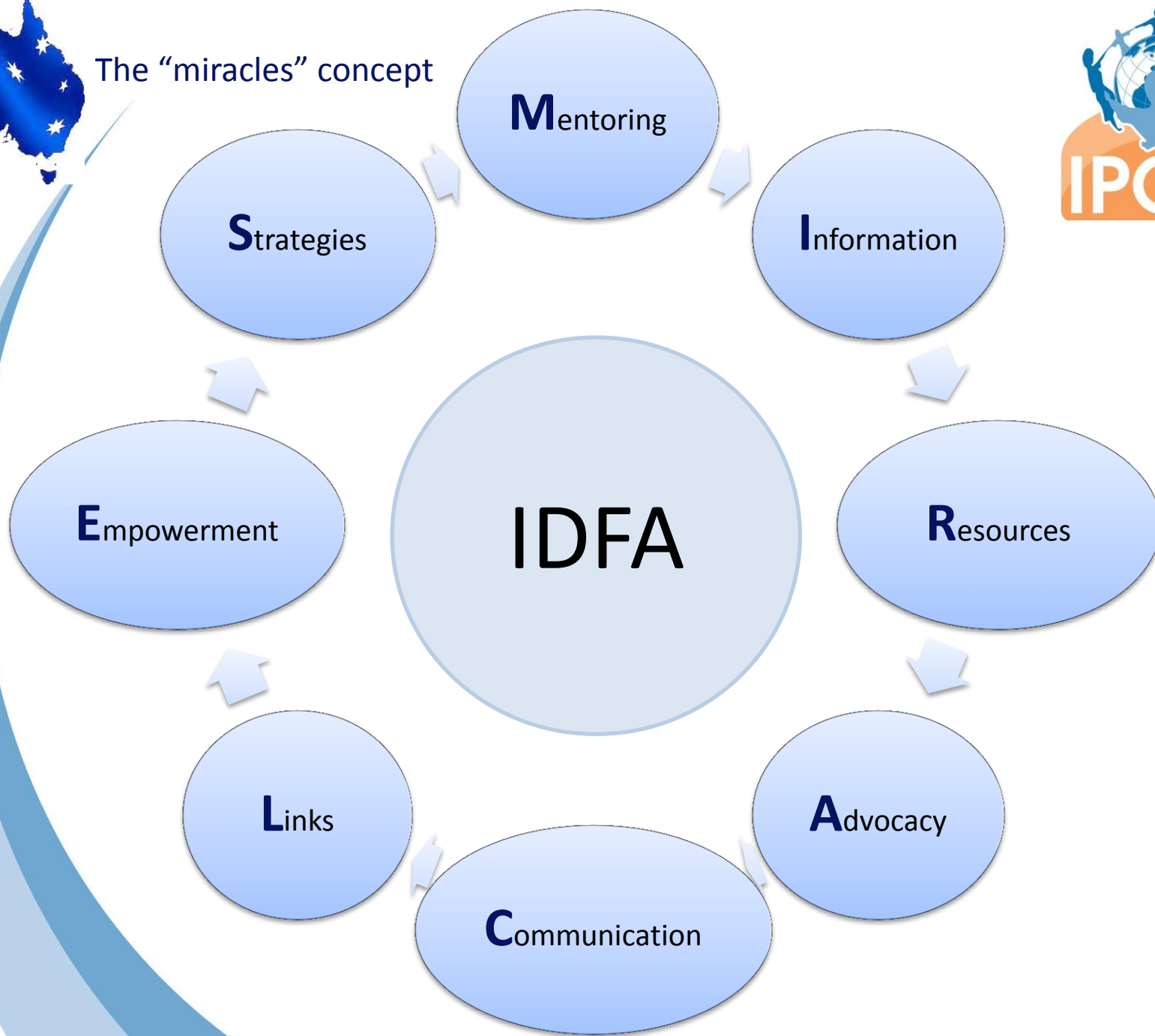
NMO 10-15 years old
One minute you have a success and the next minute you feel disheartened

Finding my place
doing things by myself

child



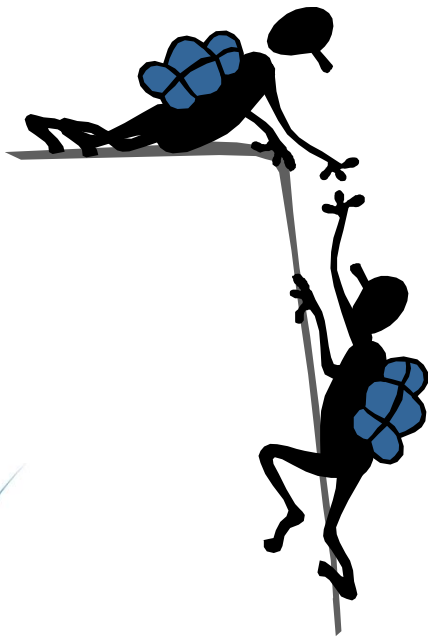
The “miracles” concept



“M”



Mentoring



Create mentors from existing members to “buddy up” with new members

Create mentors for primary immune deficiency diseases e.g. CVID mentors, XLA mentors

Create mentors for young members





Information

About PIDs



PO Box 969
Penrith
NSW 2751
1800 100 198
www.idfa.org.au

*Raising awareness &
supporting people with
Primary Immune Deficiencies*

IDFA YAMs (Young Adult Members) Closed Facebook Group

Hello and Welcome!

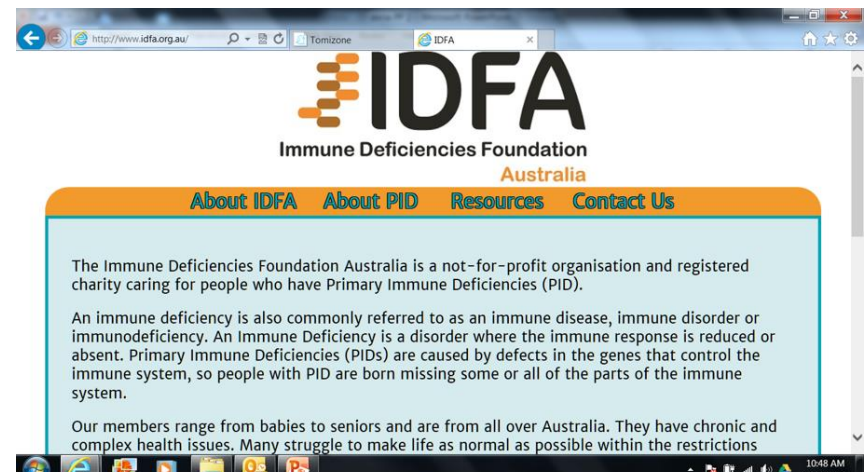
This Facebook group has been designed especially for IDFA's young adult members. Its purpose is to provide a place where members can connect, share ideas, have a whinge/vent (if needed) and ask questions. It is also a page where information can be shared in relation to young adult experience of Primary Immune Deficiency.

-Chloe Appleton

IDFA Youth and Young Adult Support Officer
chloe@idfa.org.au

About NMO & benefits of membership

Gather data from your members (privacy laws)



“R”



Resources

IPOPI Booklets

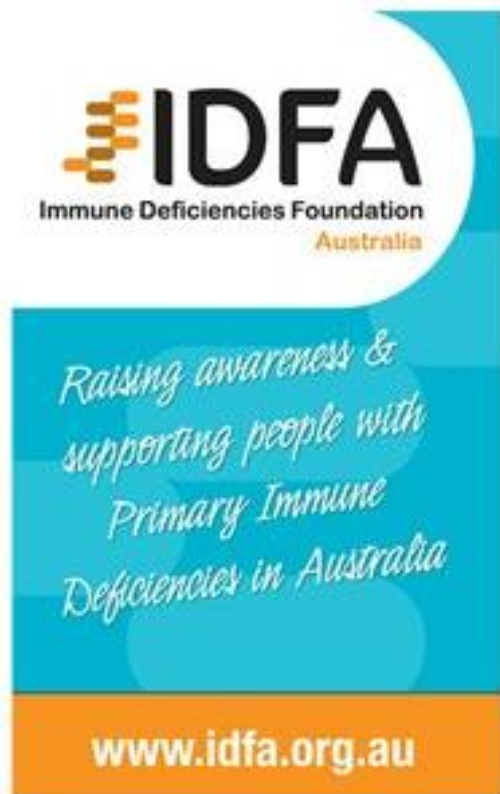
Web page

PID education





Advocacy



Advocate for treatment and
access to care

Advocate for better quality
of life

Align with your country's
immunologists and clinicians



Communication

Physicians, nurses

[Web Version](#) | [Update preferences](#) | [Unsubscribe](#) [f Like](#) [t Tweet](#) [e Forward](#)

IDFA InTouch August 2013

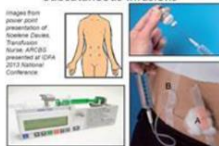
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News: SCIg update from the NBA

From September 2, SCIg (subcutaneous immunoglobulin) will be available through hospital based SCIg programs throughout Australia. This update is available at the [National Blood Authority website](#).

Subcutaneous infusions



Newsletters, teleconferences, skype, website, social media

Patient gatherings -outings, events, conferences



“L”

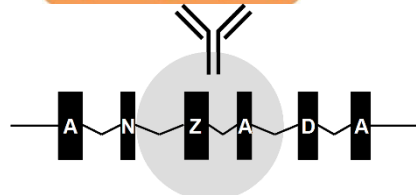


Links

IPOPI, World PI Week, Rare Disease day

Link to systems already available e.g. other NMO websites, health department, blood bank, hospitals, social workers, transition (child to adult care)

Link patients with similar PIDs and similar ages



AUSTRALIA AND NEW ZEALAND
ANTIBODY DEFICIENCY ALLELE STUDY



Immune Deficiencies Foundation
of New Zealand



World PI Week
Test. Diagnose. Treat.
22-29 April



“E”



Empowerment

Empower your members, be encouraging, supportive

Help members take control of their life

Create volunteers within your NMO to engage with those who are struggling

KINGS PARK

Help her find a cure



Annette Farrugia is organising a gala ball to raise money to help people like her son Dylan, who has a genetic immune deficiency.

Picture: DAVID SMITH

Kellie Cameron

MOTHER ORGANISES CHARITY BALL FOR IMMUNE-DEFICIENT SON

KINGS Park's Annette Farrugia has lost two loved ones to a genetic disorder that has also been passed down to her son and nephews.

She is organising a gala ball at Taylors Lakes to raise awareness of and money for a foundation supporting people with primary immune deficiencies, and is asking locals to attend.

Immune deficiencies are

caused by defects in genes controlling the immune system.

People with the disorders are more susceptible to infections, which can damage vital organs. Treatment involves regular antibody replacement therapy.

Mrs Farrugia's family is affected by an extremely rare primary immune

deficiency called X-linked agammaglobulinemia.

Her brother, who had the disorder, died months after having a double lung transplant. A nephew died waiting for one. Mrs Farrugia's son, six nephews and one great nephew have also been diagnosed with the disorder affecting only males. Females are the carriers.

She said her son Dylan, 21, had his first antibiotic infusion aged just six weeks old. He has been hospitalised countless times with infections, and required life-saving infusions every three weeks.

Mrs Farrugia hoped her fundraiser for Immune Deficiencies Foundation Australia would contribute to

finding a cure for what she described as a "horrendous" genetic disorder.

The Immune Deficiencies Foundation Australia annual gala ball, Touch of Elegance, is on April 11, 6.30pm, at Lakeside Banquet and Convention Centre.

For tickets or to donate door prizes, phone 9459 945114.

“S”



Strategies

Provide strategies for coping skills and everyday life

Vision

Assist with practical advice e.g. government programs for those who are ill

Mission

Encourage members to share their coping strategies with others

Goals

Values

Encourage sharing



I developed the **“MIRACLES”**
concept after preventing one of our
members from harm by using:

Mentoring

Information

Advocacy

Communication



This miracle was:

- ☑ *“A remarkable event or development that brings very welcome consequences”*



I love the “**MIRACLES**”
concept because it is *positive*.

I think it is better to focus on the positive
things you accomplish as an NMO,
because out of that positive, you may just
have a “**MIRACLE**”.

One miracle inspires you to try for
more... and more....

ACTIVITY:

What is your miracle?

List your:

- Name
- Country
- Miracle, something you are proud of or achievement

