WORKSHOP - WPIW Awareness





SPLIT INTO 2 GROUPS







WORKSHOP OVERVIEW: 3 TOPICS 15 MINS TO DISCUSS / 15 MINS TO PRESENT

1. PUBLIC AWARENESS	2. MEDICAL AWARENESS	3. POLITICAL AWARENESS
 GROUP 1 - Plan a social media campaign for your NMO for World Pl Week GROUP 2: What other strategies/platforms are there to get public attention to your cause with low cost? 	 GROUP 1 - Come up with ideas to raise awareness in the university/public hospitals GROUP 2 - What other low-cost ways and platforms/fora are there to raise awareness among medical professionals? Who should be targeted? 	 GROUP 1 - Try to find strategies to draw policy makers' attention to PIDs. How can you give more weight to your message? GROUP 2 - Choose an objective for your political awareness campaign and think of ways to encourage others to take part. What kind of materials can be used?



• What tools exist?

My future starts with early testing and diagnosis of Primary Immunodeficiency

World Primary (mnichocoficiency Week

22"d to 29th of April 2018

Reasing Awareness for Diagnosis and Treatment of Pl Together

🛛 worldpliwdek.org 🕊 AWorldPlWeek



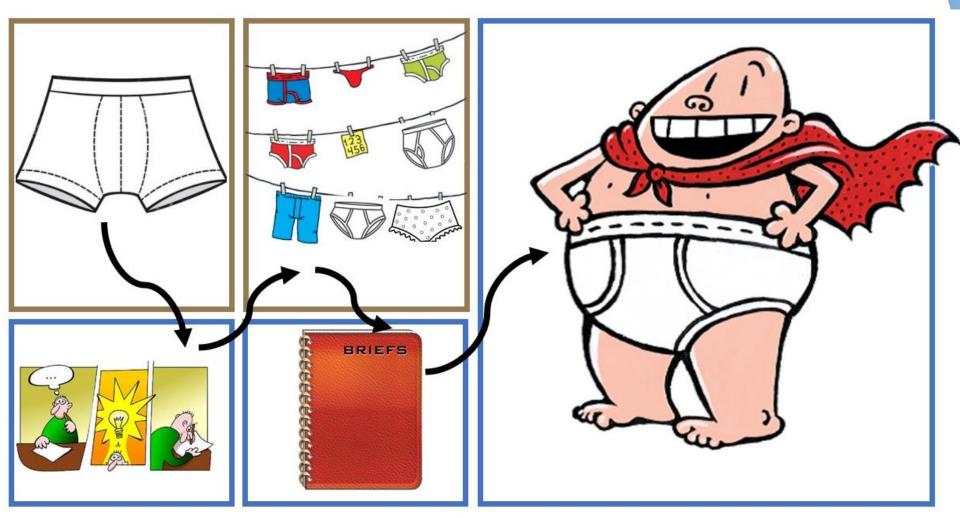


How do you use the materials?



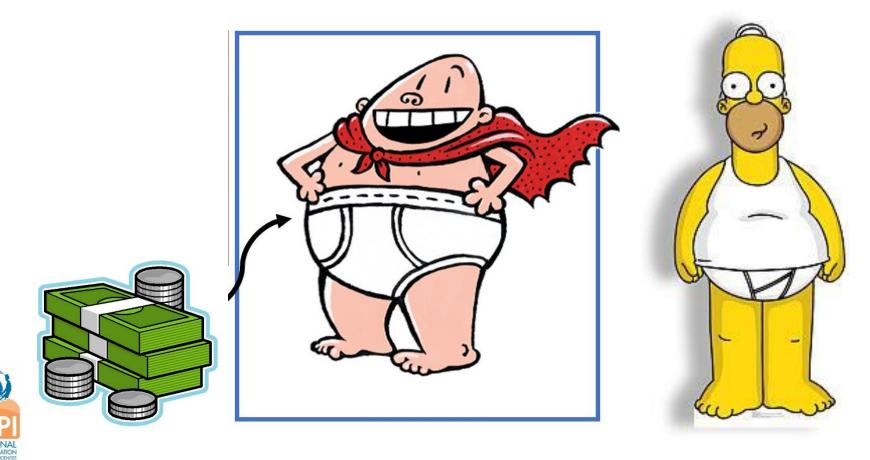


 Can you adjust the materials to match your purpose?



Can you plan a successful campaign with low resources?

Can you team up with a similar group?



 Keep It Short & Simple! (KISS)



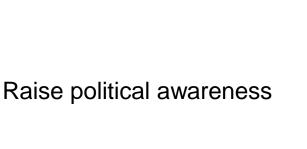
E.G. IDFA

Raise public awareness



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Raise medical awareness





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Immune Deficiencies Foundation Australia Severe Combined Immune Deficiency (SCID) Newborn Screening Position Statement

Commonly known as the "bubble boy" disease, Severe Combined Immune Deficiency (SCID) is a paediatric emergency. It is the most severe form of inherited primary immunodeficiency, a lifethreatening condition in which the body is unable to fight off serious infections.

This condition is curable with haematopoietic stem cell transplantation (HSCT) if treated in time, with best results in the first months of life.

For babies born with SCID, a delay in diagnosis may have fatal consequences. These babies initially look perfectly normal. Around the age of 2 to 3 months, they suddenly become extremely ill. As SCID is a rare condition, the diagnosis may not be considered and the special tests required for confirmation done before it is too late. The optimum time for these tests to be done is before the baby gets sick, preferably soon after birth. This enables commencement of early treatment to prevent the baby from deteriorating, increasing the chance of successful curative treatment.

The Immune Deficiencies Foundation of Australia recognises the severe impact undiagnosed and untreated SCID has on the infant, including serious infections, extensive hospital stays, long term organ damage and eventually death. IDFA also recognises the impact this has on the family of the infant.

Early identification, diagnosis and treatment of infants with disorders identified through Newborn Screening (NBS) is vital to preventing significant morbidity and mortality.

NBS for SCID prevents infant deaths from SCID and increases the chance of successful cure by Haematopoietic stem cell transplantation (HSCT).

SCID fulfils all the internationally recognised criteria for a clinical condition to be screened for at birth through NBS using the Standard Guthrie (dried blood spot) sample.

NBS for SCID should be mandatory in all States and Territories of Australia, as it is in New Zealand, Norway, Ontario, Canada, Spain, Qatar (private clinics), Singapore (private clinics) and most States of America. There are pilot studies in Japan, France, Italy, Germany, Saudi Arabia, Slovenia and Sweden.

IDFA supports the introduction of Newborn Screening for SCID in Australia to prevent further infant deaths and the enablement of curative treatment within the first months of life to ensure the best health outcome and quality of life of infant patients.

More information can be found at:

http://www.idfa.org.au/support-newborn-screening-for-severe-combined-immune-deficiency-scid/

"I wholeheartedly support the introduction of Newborn Screening for SCID in Australia. Newborn Screening for SCID may have saved my son's life. My hope is that with the introduction of this important test that no more babies will die from this condition" Bianca (mother)

"If Australia had Newborn Screening for SCID, my baby's SCID would have been diagnosed earlier reducing the risk of multiple infections and his HSCT treatment would have been conducted earlier, improving his current quality of life-Tracey (mother)



IDF

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1. PUBLIC AWARENESS - 15 MINS TO DISCUSS

Group 1: Plan a social media campaign for your NMO for World PI Week

Group 2: What other strategies/platforms are there to get public attention to your cause with low cost?



Concept: Get an understanding which tools and settings to use to reach a large audience to raise maximum awareness with minimal cost.

2. MEDICAL AWARENESS - 15 MINS TO DISCUSS

GROUP 1 - Come up with ideas to raise awareness in the university/public hospitals

GROUP 2 -What other low-cost ways and platforms are there to raise awareness among medical professionals? Who should be targeted?



Concept: Come up with ideas on how to raise awareness with physicians, to encourage referrals to immunologists & to raise diagnostic rates of PIDs.

3. POLITICAL AWARENESS - 15 MINS TO DISCUSS

GROUP 1: Try to find strategies to draw policy makers' attention to PIDs. How can you give more weight to your message?

GROUP 2: Choose an objective for your political awareness campaign and think of ways to encourage others to take part. What kind of materials can be used?



Concept: Use World PI Week tools & momentum to raise awareness on policy level. This is a huge priority in this region, with limited access to diagnostics and treatment, and financial burden of treatment falling on families.

1. PUBLIC AWARENESS - 15 MINS TO REPORT

Group 1: Plan a social media campaign for your NMO for World PI Week

Group 2: What other strategies/platforms are there to get public attention to your cause with low cost?

Lessons learnt:

- What different ways/platforms/strategies are there to reach out to the public with low cost
- what to consider in order to plan a successful awareness and social media campaigns



PUBLIC AWARENESS: Group 1: Plan a social media campaign for your NMO for World PI Week

- Theme: follow WPIW theme
- Use patient organisation's social media page
- Testimonials, posters, video
- Endorsements,
- Infographics visual materials
- Press releases to online media
- Video similar to last year
- Email blast
- People affected with PID
- HEALTHCARE PROFESSIONALS
- Event promotion
- Have a committed team to promote the campaign
- TIPS:
 - PLAN WELL AHEAD
 - Create a schedule



PUBLIC AWARENESS GROUP 2 - What different ways/platforms/strategies are there to get public attention to your cause with low cost

- March with placards
- Pamphlets
- Roadshow with logo
- drive around in a hired bus with external posters and speak to people to explain PIDs and give out pamphlets
- Doctor patient meetings
- Balloon day
- Radio day, live broadcast
- Link your cause with something exciting!
 - Interesting costumes for the day (e.g. Astronaut for bubble boy)
 - Bubble soccer tournament maybe with soccer stars excercise is healthy!
 - Ice bucket challenge
 - Public, free events with sports/music/lottery/other entertainment
- Find sports companies, foundations, theatre groups, entertainment companies who are willing to co-organise your event.
 - Promote well to get a lot of people there

Use WPIW materials, they are free.



2. MEDICAL AWARENESS - 15 MINS TO REPORT

GROUP 1 - Come up with ideas to raise awareness in the university/public hospitals

GROUP 2 -What other low-cost ways and platforms are there to raise awareness among medical professionals? Who should be targeted?

Lessons learnt:

- different ways to reach the medical audience with low budgets
- identify platforms best suited for the region for reaching medical audience
 - how teaming up with the doctors will help reach your common goal

MEDICAL AWARENESS GROUP 1 - Come up with ideas to raise awareness in the university/public hospitals

- Determine audience
- Medical students
- Know doctors who give lectures to medical students
 - GPs, Paediatricians, Immunologists, Alumni
 - MED STUDENTS
- Lunch talk/event (a booth at a hospital)
- Quiz with free cinema tickets and donut
- DOCTORS
 - testimonials
- Send a PID patient to talk in an event
- Give out study credits
- HOSPITALS/UNIVERSITIES
- Pamphlets (tone down for universities)
- Short educational movie/video
- send printed info materials/warning signs to doctors, maternity clinics, nurses
- hang posters in hospitals



MEDICAL AWARENESS GROUP 2 - What other low-cost ways and platforms are there to raise awareness among medical professionals? Who should be targeted?

- Educational workshops for students (e.g. Difficult case conference)
- Med students simple leaflets about PID
- Design a giant tree postcard, have it in a booth at conference/hospital/uni
 - apple sticker paper for passers by to send wishes to patients
- Attractive people to hand out educational material (celebrity to support your cause)
- raise awareness for pharmacy students
- Target people who are front line GPs
- Pamphlet delivery, mass emails, look up specialty conferences and workshops and ask for a session to discuss PIDs
- Cover as many hospitals as possible
- Awareness booth rotation in different hospitals
- WPIW video played
- Write a letter about PID to specialist/Societies newsletters
- Keep a mailing list
- Build a list of ùseful people/contacts
 - medical writers, journalists, etc

contact local medical journals,

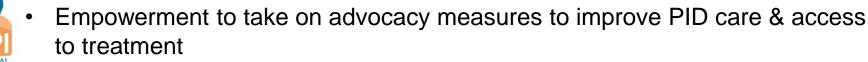
reach out to nurses

3. POLITICAL AWARENESS 15 MINS TO REPORT GROUP 1: Try to find strategies to draw policy makers' attention to PIDs. How can you give more weight to your message?

GROUP 2: Choose an objective for your political awareness campaign and think of ways to encourage others to take part. What kind of materials can be used?

Lessons learnt:

- Choosing one main objective is the most effective way to advocate
- which tools can be used for which objective?
- What are different ways of engaging with policy makers
- Who to reach out to make allies





POLITICAL AWARENESS GROUP 1: Try to find strategies to draw policy makers' attention to PIDs. How can you give more weight to your message?

- Now how your political system works
- Meet govt and get them to give opening speech at family day (so they have to research PID)
- Identify 3 key messages for govt, e.g.
 - 1. Diagnosis
 - 2. Lack of treatment options
 - 3. effect of PI on families and patients: cause and cost (requires research)
- Target audience: Ministry of health, congress, local govt
- From local perspective: invite MOH rep for involvement and connection
- join a high exposure event
- Join up with haemaophilia, thalassaemia: Get patient voices together with a single theme, create a single event at the same time
- Leverage IPOPI: localised version on advocacy tools for PID
- Presentation and infographics localised for govt and the message
- Some politicians want to be helpful
- Sometimes you will present everything and the politician will ask: how can I do that? Be prepared for this question. Know what s happening at political level. Election coming up? Policy reviews? Have an answer!



Find out drug licence Committee, write to them, offer your help as an expert Always follow up, thank stakeholders annually, invite them to a dinner, have a patient thank them, include media

Focus on long term goals, create win-win situations, have concrete figures

POLITICAL AWARENESS GROUP 2: Choose an objective for your political awareness campaign and think of ways to encourage others to take part. What kind of materials can be used?

- SCIG availability/reimbursement of Ig therapies for adults, reimbursement of BMT, plasma donations.
- Involve stakeholders, patients, families, doctors, pharmaceutical companies
- create long term relationships with stakeholders
- Produce information to give better understanding to stakeholders
- Include cost effectiveness
- Use WHO statements, list of essential medicines, APEC guidelines
- Use infographics
- Make stakeholders remember you: follow up and keep communicating
- Include media
 - use patient stories, use success and sad stories so politicians can hear stories and understand: empathy/connection – to help achieve objectives
- WPIW is a momentum but only 1 part of the advocacy timeline
- Even when you feel comfortable, never let advocacy disappear
- Come with what you want to ask, but also what you can offer (win-win)
- Present challenges, solution and outcome (patient stories good and bad) so politician cannot deny the issue

Simple messages e.g. I want to live, you are my medicine

Be a partner on advisory committees that have a say (Rare diseases etc)

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