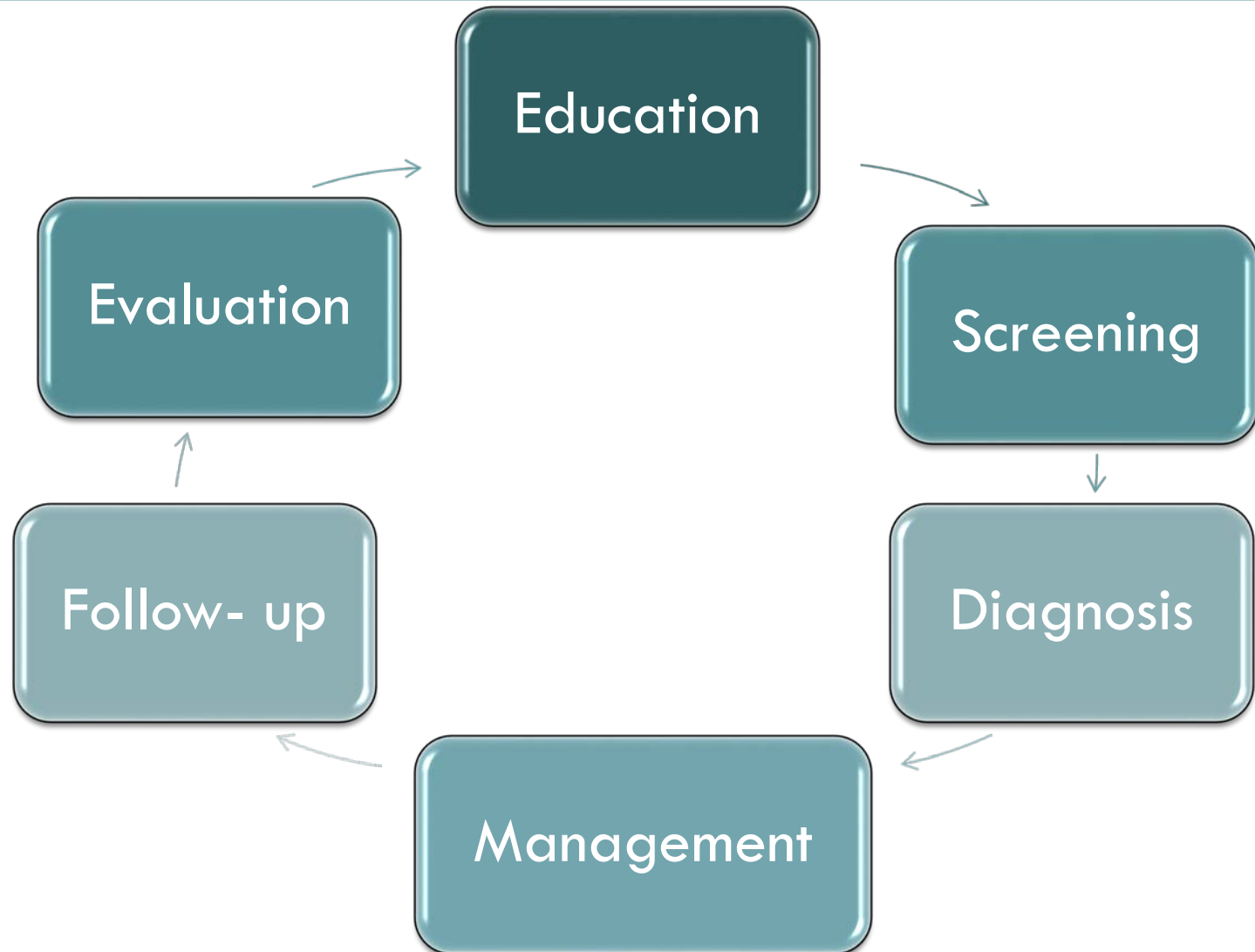
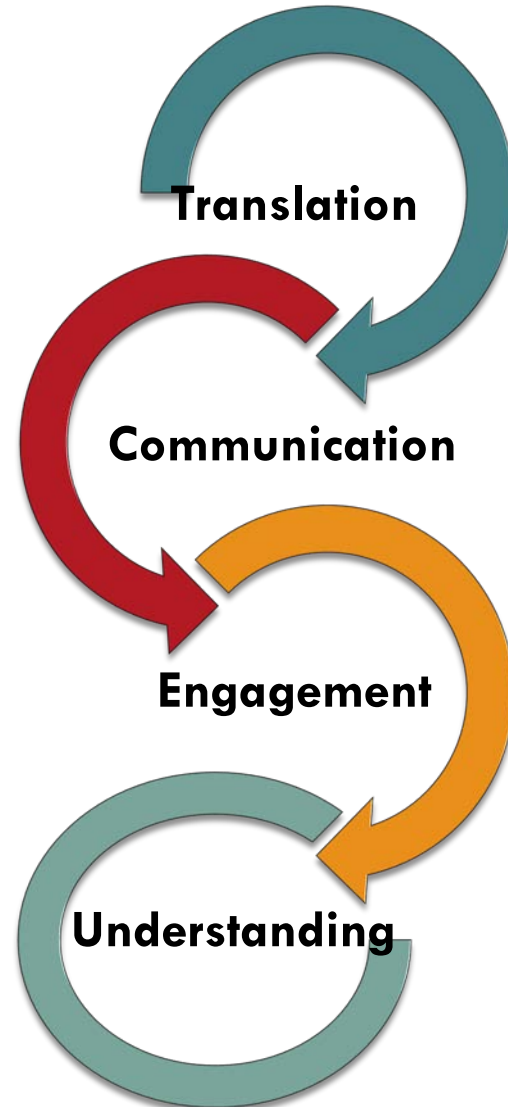


ADVOCACY, PARENT PERSPECTIVES, AND EDUCATION

Newborn Screening System



What Do We Mean By Education?



What worked/ works for SCID

- Grassroots advocacy
- Dramatic results
- Public's previous exposure
 - Lorenzo's Oil
 - "Bubble Boy" disease
 - Advertisements/ PSAs
- State level Advocacy



Public Awareness: Social Media



Life of Riley

August 8, 2014 · 🌐

The Centers for Disease Control and Prevention says 100 newborns are diagnosed each year. The babies are born healthy but can be threatening within a few months.

One year ago today I woke up dreading a phone call...I knew it was coming. Late in the day it was confirmed...Riley had SCID. No fluke, no false positive and no immune system.

Today I woke up to a sick baby. That's right. Our first illness outside hospital walls happened today. Poetic? Ironic? Terrifying? Uh huh.

According to the doctors her little body should be able to fight this off all on its own...it may take her longer and hit her harder but she should be just fine. ... [See More](#)



Like Comment

Contemporary Pediatrics
The US Food and Drug Administration (FDA) has a test for severe combined immunodeficiency (SCID)

Regional

Like Page

video explains it well from a family in region are screening newborns for SCID? <https://www.youtube.com>

Newborn Screening in Illinois

A family talks about how newborn screening for Combined Immune Deficiency (SCID) in Illinois has changed their lives and how important it is

ILLINOIS.COM

Importance of newborn screening in Illinois

Due to recurring infections and could develop pneumonia, and other complications. Newborns have blood drawn at least...

Boost Post

Evaluation/ Scale



Where Public Gets
Pregnancy/ Parenting
Information



Materials/ Videos/
Content Created

Why educate pre-screening

- Help to build awareness of public health
- Increase general knowledge of NBS
- “Plant a Seed”
- Put a face to NBS



Key items to cover post-screening

- Follow up protocols
 - Immediate next steps
 - Support groups/ networks
 - Potential outcomes
-
- Important for information to be tiered/revisited



Where are People Seeking Information?

- Family/ Trusted Communities
 - Religious
 - Social
- Online
 - BabyCenter
 - The Bump
 - What to Expect When Expecting
- Physician/ Healthcare Provider/ Prenatal Classes
- Word of Mouth



Messaging

- Identify the audience
- How to get their attention
- Get them to listen to the message
 - ▣ Hear/ See it multiple times (7x)
 - ▣ Understand/ Accessible
 - ▣ Believe it/Complementary to other information
- What is in it for me?

- (adapted from Church, T. *Strategies for Successful Public Health Messaging*
<http://www.nwcphp.org/documents/training/hot-topics-1/successful-messaging-notes>)



What Do We Need In the ~~Future~~ Today?

- Re-Establish Value
- Consistent Message multiple places, multiple sources
- Embed in established communications channels
 - Go Find Information - ~~Brochures, static sites~~
 - Information Finds You -New Technologies: apps, mobile friendly sites, texts
- Is there a shared message around NBS? Around the addition of new conditions?





Thank you

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