The Care and Feeding of Someone with CGD

M. ELIZABETH M. YOUNGER CRNP, PH.D
ASSISTANT PROFESSOR, PEDIATRICS
JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE
BALTIMORE, MARYLAND
Disclosures

CSL BEHRING: CONSULTANT, RESEARCH SUPPORT
RMS: CLINICAL ADVISORY PANEL
BIO PRODUCTS LAB: ADVISORY BOARD
HORIZON PHARMA: CONSULTANT; ADVISORY BOARD
IMMUNE DEFICIENCY FOUNDATION: NURSE ADVISORY COMMITTEE
Chronic granulomatous disease is... 

A chronic illness 
that affects your child’s life
Chronic granulomatous disease is NOT...

His LIFE!
Basic Needs

Eat well

Exercise

Get plenty of rest
Some other important needs:

- an annual well visit with the child’s PCP
- Get ALL recommended immunizations, especially an annual influenza vaccine (and oh btw...everyone in the family needs a flu vaccine, too)
Needs: Medications

- Give/take all medications as prescribed
- DO NOT give/take over the counter medications without consulting your provider
- Tell your provider if you cannot:
  - Get medications
  - Or if your child cannot
  - Take the medications
  - Tolerate his medications
A word about medications:

- Giving Interferon gamma (Actimmune®)
  - Establish a routine
  - Don’t make the procedure a “Big Deal”
  - Don’t let your distress or anxiety show
  - Consider a reward program
  - Remember: a child may not be able to tell you he doesn’t feel well after his shot
  - Don’t ever give the shot while the child is in his bed
  - Premedication with acetaminophen or ibuprofen is usually fine
Medications: Antibiotics

- Establish a routine, before brushing teeth is a great time
- Most pharmacies can flavor suspensions
- Teach pill swallowing as soon as possible
Know what to call your provider about:

Usually that is:

A fever

A cough, especially if it is productive

A sore or wound that is red, painful or draining

....Or anything else that worries you
Do’s and Don’t’s
Don’t

Swim or play in the ocean or fresh water (ponds, streams, lakes)
Do

Cool off in the swimming pool
Don’t

Soak in a hot tub
Do

Play in a bath with lots of bubbles
Don’t

Play around mulch, hay, wood chips, mulch, fallen leaves, grass clippings, other yard waste
Do

Something fun while someone else rakes leaves or mows the lawn
Do

Avoid damp or dusty places like caves or (some) basements
Do

Avoid areas of construction or remodeling
But, DO

Just about everything else!
Just GO FOR IT!
Questions/Concerns/Comments?