The Care and Feeding of Someone with PI

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In collaboration with....

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A primary immunodeficiency is a chronic illness that affects your life.
A primary immunodeficiency is NOT...

Your LIFE!
DO:

- Take care of yourself
  - Eat well
  - Exercise
  - Get plenty of rest
Do

- Take control (as much as you want!)
- Ask for help
DON’T

- Don’t ignore signs of illness
- Hesitate to notify the appropriate provider about a new problem
- “Suffer in silence”
Some important needs:

- Have an annual well visit (physical) with your PCP
- Get ALL recommended immunizations, especially an annual influenza vaccine
- Have routine health maintenance screenings as recommended (i.e. colonoscopy, mammography, etc.)
Needs:

- Take all medications as prescribed
- NOT take over the counter medications without consulting your provider
- Tell your provider if you cannot:
  - Get your medications
  - Take your medications
  - Tolerate your medications
Needs:

- Have primary data regarding your diagnosis
- Know your medications and doses
- Know your drug allergies
- Keep this information with you ALWAYS so that it is readily accessible
- Consider using a personal electronic patient record
- Consider a living will that provides a guide to your care team and family regarding your wishes for treatment
You do need to:

- **Communicate!**
  - *All* of your providers need to know about *all* of your health problems, medications and plans for care
  - Let family members and people who matter know about your condition
  - Let these same people know how you are feeling
  - Ask your providers to talk to each other as necessary
  - Put together a Health Care Team and define the role for each team member
Who Is On Your Team?

- Health Care Providers
  - Primary Care
  - Specialists
- Nurses
- Pharmacists
- Therapists
  - PT, OT, Counselors
- Support Staff
- Social Workers
- Family/Friends
GOAL

Establish a Therapeutic Relationship...
A partnership where you and your care team work together to optimize your health
Benefits of a Therapeutic Relationship

- Know up-to-date and accurate information about all of your diagnoses
- Participate in making decisions about your medical care
- Manage your symptoms and get good follow-up care
- Make the most of the time you have with your health care team
- Reduce stress by making sure your questions are answered and your concerns are addressed
- Feel confident that you are getting the best health care
In an ideal world, all healthcare providers would....

- Be patient
- Be understanding
- Have unlimited time to answer your questions
- Know exactly how to explain things so you could understand
- Be able to fix all of your healthcare problems

but, the reality is.....
Think about....

- What kind of communicator are you?
- What kinds of communication work well for you?
- What kind of relationship do you want with your care providers?

Once you’ve answered these questions, you’re ready to:

Choose a Provider....
Choosing Providers

OR

OR
Communication Responsibilities

- Your team’s responsibilities include:
  - Be respectful
  - Be truthful
  - Be responsive
  - Be accurate
  - Be a good listener

- Your responsibilities include:
  - Be respectful
  - Be truthful
  - Be responsive
  - Be accurate
  - Be a good listener
In addition to Responsibilities, you also have Rights

1. The right to have your condition and treatment explained so that you can understand it
2. The right to a second (or third or fourth or...) opinion
3. The right to make decisions about treatment and to refuse treatment, if you so choose
4. The right to have copies of medical records and lab reports
5. The right to be treated courteously and with respect
6. The right to privacy
"I watched ER and now I'm getting a second opinion from Chicago Hope."
Decisions about Treatment

Should **ALWAYS** be made collaboratively **AFTER ALL** the options are understood...
Don’t let PI rule your life
Just GO FOR IT!
Questions/Concerns/Comments?