Be Your Own Healthcare Advocate
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Topics

▪ Learn!
  • Basic Facts about PI

▪ Live!
  • Living with & Managing PI
Primary Immunodeficiency Diseases
Acronym Confusion

PI
PID
PIDD
You Look Good!
How Do I Tell Others About PI?
Learn!
Facts about PI
What Are Primary Immunodeficiency Diseases?

- Primary immunodeficiency diseases (PI) are a group of more than 350 rare, chronic disorders in which part of the body’s immune system is missing or functions improperly.

- While not contagious, these diseases are caused by hereditary or genetic defects.
Who Does PI Affect?

- Approximately 250,000 people diagnosed with PI in the U.S. (1 in 1,200), and thousands more go undetected.

- Some disorders present at birth or in early childhood, but they can affect anyone, regardless of age or gender.

Source: 2006 IDF National Prevalence Survey
What Are the Symptoms of PI?

- Severe
- Persistent
- Unusual
- Recurrent
- Runs in the Family
How Is PI Diagnosed?

- Medical and family history, physical exam, blood and immunoglobulin level tests and vaccines to test the immune response may be included in the diagnosis process.

- **Over half** (52%) of individuals with PI are 30+ years of age when diagnosed.

- Average length of time between onset of symptoms & diagnosis is 15.3 years.

Source: 2012 IDF National Patient Survey
How Is PI Treated?

- Depends upon specific diagnosis
- Various treatments available:
  - Antibiotic Therapy
  - Antifungal Therapy
  - Gamma Interferon
  - Gene Therapy
  - Granulocyte-Colony Stimulating Factors (G-CSF)
  - Hematopoietic Stem Cell Transplant (Bone Marrow Transplant)
  - Immunoglobulin (Ig) Replacement Therapy
  - PEG-ADA Enzyme Therapy
Live!
Living with & Managing PI
YOU Are the Coordinator of Your Care
Who Are the Members of Your Team?

- Family
- Friends
- Doctors
- Nurses
- Psychologist
- Pharmacist
- Specialty Pharmacy
- Social Worker
- Insurance Company
- And More…
"Before anything else, preparation is the key to success."

~ Alexander Graham Bell
Understand Your Rights

- Medical Information
- Choice of Healthcare Provider
- Involvement in Healthcare Decisions
- Fair Treatment & Non-discrimination
- Privacy & Protection
- Grievances
Save Important Information!

- Diagnosis information
  - Who made your diagnosis?
  - When?
  - Based on what data?
    - Treatment history
    - Lab data

- Documentation
  - Records regarding this information
  - Don’t assume someone else has these data
  - Consider using IDF ePHR

This information will help you manage treatment and insurance issues!
At every appointment request copies of everything for yourself and copies of everything to be sent to all providers.

Track medications, allergies, infections, etc.

Store pamphlets, medication and side effect inserts, and important papers and phone numbers in one place such as a file, notebook or IDF ePHR.
Immunoglobulin (Ig) Therapy

- More than 4 out of 5 individuals with PI report being treated with immunoglobulin (Ig) replacement therapy, which is the standard of care for most antibody deficiencies.

- You have options when it comes to Ig therapy.

- Work with your healthcare provider to decide what works best for YOU!

Source: 2012 IDF National Patient Survey
Ig Therapy: Know Your Options

- **Product**
  
  There is not a generic Ig product.
  
  Find a product that works for you.

- **Mode of Administration**
  
  - **IVIG** – Intravenous
  
  - **SCIG** and **fSCIG** – Subcutaneous, Facilitated Subcutaneous
    
    Multiple options for pumps, needle sets and tubing exist.
    
    Consult your care team to ensure you have the correct combination.

- **Site of Care**
  
  - IVIG administered by an RN in the home, infusion suite or hospital
  
  - SCIG/fSCIG administered by the patient/caregiver at home
Ig Therapy: Know the Basics

Information to Know

- Ig product name
- Ig manufacturer’s name and patient assistance programs
- Amount Infused, frequency and rate
- Name and dose of pre and post infusion medications

Take Action

- Report infusion related side-effects to your healthcare provider.
- Track Ig product lot numbers and all infusion related information
  
  IDF ePHR: www.idfephr.org

- Register with the Patient Notification System for product recall info.
  
  www.patientnotificationsystem.org
NEW: IDF Guide to Ig Therapy

• Developed for patients and caregivers to help increase understanding of Ig replacement therapy.

• An increased understanding puts patients and caregivers in a better position to make informed decisions regarding care.

• These informed decisions will in turn improve overall health.

Available at No Cost to You:
Stop by the IDF Table to Pick Up Your Guide!
The Appointment

11

DOCTORS
APPOINTMENT

12
The Question...

And how are you doing?
Notes for an Appointment

- Your questions.
- How you have been feeling (physically and emotionally).
- Changes in your body.
- Your worries and concerns.
- Issues related to treatments and side effects.
- Insurance and benefit coverage that could affect healthcare choices.
What Did They Say?

- Take notes during the appointment.

- Consider bringing a supportive family member or friend with you to appointments. That person can write down the information you receive and help you ask questions.

- If there is no one to who can go with you, ask your healthcare provider if you can record the meeting.
Communicating with Your Healthcare Team
I’m Sick – Now What?

- Prepare for when you get sick
- Develop an **illness protocol**
  - Ask your immunologist:
    - “How will I get my questions answered between scheduled appointments?”
    - “When and where I should go when I get sick?”
  - Prepare for possible emergency room and/or urgent care visits
    - Have your immunologist contact information and/or letter from your immunologist
    - Have basic health information (such as IDF ePHR)
  - Go the extra mile to prepare for ER/urgent care visits
    - Print or have access to IDF handbook chapter on your diagnosis
    - Have copy or digital access to IDF Diagnostic & Clinical Care Guidelines
Signs of a Communication Breakdown

- You don’t feel like you are part of your care team.

- Healthcare team members aren't open to discussing your questions, concerns or problems.

- You are leaving an appointment with unanswered questions or a lack of information.
Improving Communication

- Be prepared with notes.
- Ask questions.
- Talk to other members of your healthcare team.
- Get a second opinion.
Good Communication Will Help You…

- Find out about current information related to your PI and treatment.
- Participate in decisions about your medical care.
- Better manage your care.
- Make the most of the time you have with your healthcare team.
- Reduce stress by making sure your questions are answered.
- Feel confident that you are getting the best healthcare.
IDF Is Here for YOU!

800-296-4433

www.primaryimmune.org/ask-idf