The Intersection between Public Policy, Health Insurance and the Patient Voice

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IDF Advocates for:

- Access to Quality Care
- Screening and Diagnosis
- PI Community Support
- Research and Emerging Therapies

Help individuals with PI receive lifesaving care!
Extending Medicare IVIG Demo
- Extended by Congress to December 31, 2020
- IDF is now advocating for this to become a permanent benefit

Ensuring Medicare reimbursement for in-home SCIG
- Medicare mandated to provide temporary services payment beginning January 1, 2019
- This temporary payment addresses the gap in care until reimbursement under the 21st Century Cures Act for training and monitoring kicks in on January 1, 2021
- IDF is currently advocating to ensure full implementation

Maintaining patient protections under the ACA
- Currently intact but requires continued advocacy to maintain
Advocacy Initiatives
Working on Behalf of Patients

Addressing high co-insurance and specialty tier policies
  • Led campaigns in Nevada and Iowa
  • Supporting efforts in MI, NJ, OH, OR, MA and PA

Opposing inappropriate payer drug guidelines and limitations on sites of care
  • Have seen policy changes from Aetna and BCBS due to IDF’s advocacy

Facilitating SCID newborn screening in all 50 states
  • Currently, 47 states are screening, accounting for 94% of all newborns in the U.S.
  • Continuing advocacy in remaining three states: Alabama, Indiana and Louisiana
Advocating for Patients with Payers

- IDF communicates with payers on policies that adversely affect people with PI including:
  - Poorly written or out of date Ig medical guidelines
  - Restrictive formularies
  - Narrow networks of providers
  - Restrictions on sites of care
- IDF partners with immunologists to educate and help resolve issues with payers
- IDF is currently planning an event with payers to educate them about issues unique to the PI community
Types of Insurance Plans

- **Private**
  - Individual policies purchased through the Health Insurance Marketplace or outside the Marketplace
  - Employer-sponsored

- **Public**
  - Medicare
  - Medicaid/ CHIP
  - VA Benefits/TRICARE
Important Dates

Open Enrollment for 2019

ACA Marketplace
November 1 – December 15, 2018
for January 1, 2019 start date

Medicare
October 15 – December 7, 2018
for January 1, 2019 start date
Types of Coverage in the ACA Marketplace

Bronze, Silver, Gold, and Platinum Plans

- All plans cover the same benefits and cap annual out-of-pocket expenses at:
  - $7,350 for an individual and $14,700 for families (2018)
  - $7,900 for an individual and $15,800 for families (2019)

- The **big difference is cost sharing** through out-of-pocket (OOP) expenses including annual deductibles, co-payments and coinsurance.

- To get an idea of the true cost of coverage, consumers have to **add up premiums and their expected out-of-pocket costs**.

- A Gold or Platinum plan that has a higher premium may be the better buy when OOP costs and premium subsidies are taken into account—especially for individuals with chronic, rare diseases needing on-going and expensive treatments.
Medicare Basics

- Part A – Hospital Coverage
- Part B – Medical Coverage
- Part C – Medicare Advantage Plans offered by private companies. Includes Part A and Part B coverage. Most also include prescription coverage (Part D).
- Part D – Prescription Drug
- Part F and Part G – Medicare Supplemental Coverage (Medigap)
Medicare Basics (continued…)

Many options available so investigate to see what will work best for you

- Ig therapy is covered under the Part B medical benefit at 80%

- Medigap (Part F or G) is needed to help with remaining 20%

- Medicare advantage plans are sold as “All in one” … but many patients have reported to IDF that they have a 20-30% coinsurance for Ig

Make sure you know the coverage before enrolling!
State Health Insurance Assistance Program (SHIP)

- Since plans vary state by state and even sometimes by county, every state has SHIP that provides counseling services to Medicare beneficiaries.
- They can go over the specifics of the plans you are eligible for and assist Medicare beneficiaries in making educated, informed decisions on their healthcare benefits.

To find your state’s SHIP contact information, please go to:

Every Insurance Plan Is Different: Comparing Plans and Coverage Details
What to Know Before Purchasing an Insurance Plan

- What is my out-of-pocket maximum?
- Do I have a deductible?
- Is my deductible included in the out-of-pocket maximum or is it in addition to the maximum?
- Medical and prescription plan
- How is immunoglobulin (Ig) therapy covered?
- Coinsurance
- Co-pay
- Do I have options for site of care?
- Are there out-of-network benefits?
Out-of-Pocket (OOP) Maximum Limit

What expenses are included in the OOP?
- Deductibles
- Co-payments
- Coinsurance

What expenses are NOT included in the OOP?
- Premiums
- Non-covered services
- Out of network
Visit the **IDF Patient Insurance Center:**
[www.primaryimmune.org/patient-insurance-center](http://www.primaryimmune.org/patient-insurance-center)

- Download the **IDF Health Insurance Toolkit**

  It contains facts, resources, and comparison worksheets to help you choose the best plan!
Remember…

- Policy affects everyone whether you have private or public health insurance
- Current issues may not pertain to your situation now but they will affect you because…
  - You will one day move to Medicare
  - Private insurers often follow Medicare coverage rules/regulations

“The Only Thing That Is Constant Is Change” - Heraclitus

So make sure to stay up to date on healthcare issues!
Grassroots Advocacy Opportunities

- Health Access Advocates: advocate for the PI community in your home state.
- IDF 2018 Advocacy Retreat in Annapolis, MD: PI community members in the mid-Atlantic region learn how to be effective advocates in their state legislatures.
- Sign up for IDF Action Alerts to make your voice heard to policy makers.
- To learn about issues affecting the PI community, check out the Advocacy Channel.