

Talking Points for Your Visits

1. INTRODUCTION

- Thank you for taking time to meet with me today!
- I am here as a volunteer with the Immune Deficiency Foundation, representing individuals and families with Primary Immunodeficiency Diseases.
- Primary Immunodeficiency Diseases –or PIDD – are a group of over 150 genetic or intrinsic disorders in which part of the body's immune systems is missing or does not function properly.

2. TELL YOUR PERSONAL STORY! BRIEFLY (in 1 minute)

- A** Diagnosis of primary immunodeficiency disease:
- What it is like having PIDD or having a child who has PIDD
 - Length of time to be diagnosed
 - Importance of having access to IVIG
 - What it is like being on IVIG
 - Description of the infusion
 - How long your infusion lasts
 - Types of side-effects
 - Importance of having access to your specific brand of IVIG
 - Importance of the site of care you receive it in
- If you are a Medicare recipient--how the change in reimbursement has affected you
 - Denial of care
 - Change in site of care
 - Preferred brand of IVIG, dose, frequency of infusions
- B** If you are not a Medicare recipient-- concerned because what happens to Medicare might happen to private insurance.
- If private insurance plan has changed its reimbursement rate and it has affected your care, please share that information.
 - If you are a healthcare provider, please share any information regarding the impact reimbursement has had on the health of your patients.

3. DISCUSS IVIG THERAPY

- These antibody deficient patients require chronic replacement therapy consisting of intravenous immunoglobulin infusions (IVIG) to protect individuals from frequent life-threatening infections and debilitating illnesses. Without IVIG, patients have a poor quality of life that eventually leads to disability and potential death. Access to IVIG for primary immunodeficient patients is a life or death situation.
- Without IVIG, the patient will eventually get a serious infection, become hospitalized and have lengthy and expensive treatments.

4. THE PROBLEM

- In 2005, CMS implemented a new payment methodology for IVIG, lowering the payment rate in all sites of care.
- This new payment methodology has prevented many healthcare providers from purchasing and administering IVIG because the cost exceeds the reimbursement payment from CMS.
- Additionally, Medicare beneficiaries are unable to receive their infusion in the home because Medicare does not reimburse for supplies and nursing. For many of these patients, with an already compromised immune system, the home is the best setting.
- Medicare beneficiaries need access to all brands of IVIG in all sites of care restored immediately.
- No patient should be denied access to their only lifesaving therapy. Denying IVIG to a primary immunodeficient patient is comparable to denying insulin to a person with diabetes

5. ASK

- Found on your appointment schedule

6. LEAVE PACKET OF MATERIALS and THANK AGAIN for the Meeting!