August 15, 2017

Congressman Ryan Costello, Problem Solvers Caucus

Dear Congressman Costello:  

RE: Healthcare Reform: ACA Repeal and Replace

It is tough to keep up with the latest developments and this uncertainty is all the more reason to communicate the needs of Oley members to our elected officials, especially you -- members of Problem Solvers Caucus.

We are encouraging all Oley members to connect with their elected officials to showcase the unique way that they obtain their nourishment – they feed themselves either parenterally (intravenously via a vein) and/or enterally (via a tube into the stomach). We realize that you cannot work on behalf of our members if you do not understand the specific healthcare needs, the daily challenges and abilities that the therapies allow them. They are contributing members of society that include members of the military, the workforce, school children, college students, grandparents and volunteers. They walk amongst us and survive and thrive. Their healthcare needs are significant if they are to maintain a reasonable quality of life. Wouldn’t it be tragic if they survived their underlying health event/crisis to become a victim of our healthcare system?

As an organization that represents people needing home parenteral and enteral nutrition (HPEN) to sustain themselves—largely a group of people with chronic health conditions—the Oley Foundation joins the Digestive Disease National Coalition, the National Organization for Rare Disorders, American Society for Parenteral and Enteral Nutrition and other organizations in advocating for health care reform that maintains some of the provisions of the Affordable Care Act (the ACA, or “Obamacare”), preserving key patient protections and respecting the circumstances of those combatting chronic and costly illnesses.

For the benefit of many of our members, we would encourage bipartisan healthcare reform that:

- prohibits pre-existing condition discrimination;
- prohibits lifetime and annual caps on benefits;
- limits out-of-pocket costs for patients in a meaningful way;
- and allows young adults to stay on family coverage until they are twenty-six years old.

Please do not hesitate to contact me if you have any questions, need additional information or simply would like me to organize testimonials. It’s important to Oley that you and your committee completely understand the needs of these unique individuals as you move forward with a plan to revise our healthcare. We’re happy to work with you and your schedule.

Thank you

Joan Bishop  
Executive Director