Hydrocephalus Association

On behalf of the Hydrocephalus Association and the over one million people living with this condition, thank you for the opportunity to submit comments on the Senate Finance Committee's Chronic Care Working Group Policy Options Document. We applaud the efforts of the working group to address the needs of those Medicare recipients living with chronic diseases, including Hydrocephalus.

Hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF) inside the brain. This condition may occur at any age, and can develop for a variety of reasons, sometimes as part of another condition. There is no known way to prevent or cure hydrocephalus. To date, the only treatment is surgical, most commonly the insertion of a medical device known as a shunt. Shunts divert the flow of CSF into another region of the body where it can be absorbed.

Older adults are primarily affected by what is known as Normal Pressure Hydrocephalus (NPH). This occurs when the ventricles of the brain are enlarged, but there is little or no sustained increase in the intracranial pressure. It is estimated that approximately 700,000 older Americans have NPH, but less than 20% receive an appropriate diagnosis. NPH is often misdiagnosed as Alzheimer's disease or Parkinson's disease, or the symptoms are attributed to the aging process. This is due to the similarity in the symptoms of NPH with these diseases, namely gait disturbances, dementia, and impaired bladder control. While NPH is one of the few causes of dementia that, with proper diagnosis and treatment, can be controlled and often symptoms reversed, it is a chronic and life-threatening condition as all the symptoms can return with disease progression due to shunt occlusion or malfunction.

The improved diagnostic and care services envisioned in the policy options document would go a long way toward improving the lives of those living with this condition. Of particular interest are the efforts to:

- <u>Improve management of multiple chronic conditions</u>. Because hydrocephalus, and particularly NPH, can co-exist with other conditions, patients must often work with multiple health care workers to address a variety of symptoms. This proposal may benefit patients by easing the administrative burdens on those health care providers working with hydrocephalus patients. Specifically, the Hydrocephalus Association suggests neurologists and their nurse practitioners should be included on the list of providers eligible to bill at the new high severity chronic care code outlined in this proposal when treating patients suffering from NPH in conjunction with other chronic conditions. This would help minimize unnecessary emergency room or specialist visits associated with misdiagnosed symptoms of NPH.

- Improve access to telehealth services. Access to care is often a primary concern for those hydrocephalus patients in rural areas. Telehealth services assist patients in their efforts to work with experts in the field. Such ongoing access is critical to screening, treatment and management of the condition. Specifically, telehealth services can connect neurologists, neurosurgeons, and specialists with patients in underserved areas and, as there are only five care centers that specialize in NPH in the country, allow the specialists at these centers to serve a much wider population. Visual screening through telehealth technology can inform initial diagnoses. Using proven clinical practices such survey methods for urinary incontinence or gait, it can also be a valuable to help physicians monitor and manage ongoing care. This would reduce costs by minimizing the number of in-person or emergency visits necessary for ongoing monitoring of treatment and would also help providers determine when an in-person assessment is necessary. Expanding the accessibility of telehealth services to rural or underserved hospitals or medical facilities as well as to the home would immensely help providers better screen and manage patients with NPH.

- Require or encourage the Centers for Medicare & Medicaid Services (CMS) to develop measures that focus on health care outcomes for those with chronic diseases. Unfortunately, many hydrocephalus patients face a return of symptoms due to a variety of factors, including the failure of shunts. The Hydrocephalus Association strongly supports the development of measures to evaluate a patient's quality of life as he or she manages NPH. Patient and family engagement, shared decision-making, care coordination, hospice and end-of-life care, Alzheimer's and dementia, and community-level measures—as laid out in the Committee's proposal—are all aspects that should be taken into account when developing health outcome measures for patients with chronic conditions. Focusing on health outcomes would allow patients with NPH and their physicians to fully explore ongoing treatment options while working to maximize the patients' quality of life.

- Ensure physicians may be reimbursed for a one-time visit following the diagnosis of a serious chronic condition: Receiving a diagnosis of NPH can be shocking and difficult for a patient to process. For eligible patients, the course of treatment requires brain surgery and continuous monitoring. For patients not eligible for a shunt implantation, the individual faces steady neurological decline into dementia and, ultimately, death. In both instances, it is crucial that patients have the resources to help them process the implications of their diagnosis before assessing and agreeing to a course of treatment. Thus, we support the working group's proposal to implement a one-time payment to clinicians that allows for a discussion of the progression of NPH, treatment options, and the availability of other resources to help them understand and manage the condition.

Finally, members of the working group have highlighted the important question of establishing criteria for identifying those patients with chronic conditions. Although we do not believe specific conditions should be included in the legislative language, should the Committee decide to do so, we urge Committee members to recognize that hydrocephalus meets any criteria under consideration.

Thank you again for the opportunity to comment on this policy options document. We appreciate your efforts to improve care for those Medicare patients living with chronic conditions like hydrocephalus. Should you have questions, please contact myself or Amanda Garzon (amanda@hydroassoc.org) at 888-598-3789. We stand ready to assist in any way.

Sincerely,

Diana Gray

Diana Gray
Chief Executive Officer
Hydrocephalus Association
ceo@hydroassoc.org