



In an effort to support collaboration between non-profits, the Chiari & Syringomyelia Foundation invites you and your organization to be a partner in the first **unite@thehill Patient Conference to be held June 23-25, 2018 at the Bethesda North Marriott Hotel & Conference Center**. Please see the attached flyer for various levels of participation.

The focus of this year's advocacy work will be to ask our Congress members to continue to support the Patient Centered Outcomes Research Institute (PCORI) programs for research. We will have presentations that will explain how PCORI works and representatives from various organizations that have received funding. This will be an educational program for organizations and patients and their families.

June 23

Saturday evening will begin with the "United We Stand Welcome Reception" which will include presentations and a display of materials from sponsoring non-profits. The reception will provide an opportunity for each sponsoring organization to update patients and their families about its work and programs that are available and provide "goody bag" materials. Patients will be able to meet in a social setting with a positive message - unity will bring us all closer to the answers that we need to find a cure.

June 24

The Sunday unite@thehill conference will include breakfast and patient centered workshops on IEPs, Social Security, etc. After lunch, the afternoon session will consist of medical presentations from Dr. Fraser Henderson, Dr. John Heiss, Dr. Jeffrey Greenfield and other physicians and professionals. **The complete program will be available on our website: csfinfo.org/uniteatthehill**. PCORI presentations will provide patients with the tools they need to advocate for funding on Capitol Hill.

June 25

On Monday morning, we grab our "breakfast to go" and head to Capitol Hill. We will be taking a group photo on the steps of the Capitol and will visit our state representatives to advocate for PCORI funding. This is a great opportunity to show patients and their

families that we all want to work together. **unite@thehill** is our chance to speak with **one voice!**

We look forward to your participation and if you have any questions or concerns, please let me know.

Most sincerely,

A handwritten signature in black ink that reads "Dorothy J. Poppe". The signature is written in a cursive style with a large, looped initial "D".

Dorothy J. Poppe

PS – Make it a weekend adventure! Washington has some wonderful attractions for the entire family. To learn more, go to washington.org.

For Sponsorships and Patient Registration, visit csfinfo.org/uniteatthehill-register.