



SERC Consumer Alliance

Workgroup Report – July 19-20, 2013

Overview

The SERC Consumer Alliance continues its efforts to support individuals and families affected by NBS & Genetic Disorders by sharing best practices, providing feedback to the clinical activities and projects, and working on consumer alliance driven project community. In the last year, consumer members have participated in various conferences, shared their experiences with others through articles on the SERC website, organized educational and fundraising activities within their states, and advocated for newborn screening and access to treatment issues.

The Consumer Alliance conducted their 6th annual face-to-face meeting July 19th – 20th, 2013 at the SERC/SERGG meeting in Asheville, NC. The agenda included a review of HRSA and SERC activities, state needs and successes, emergency preparedness communication planning, medical home and transition, the Genetic Alliance consumer network, NBS Connect, and a review of state needs. Invited speakers and non-consumer participants also enriched the meeting.

The following consumers attended the 2013 meeting:

Kristen Vanags (Georgia), Anna Parker (Georgia), Melissa Perez (Florida), Jodi Kotrady-Hatin (Florida), Kristy Tunnell (Mississippi), Sherry Burney (Tennessee), Vail Brennan (North Carolina), Stephanie Harry (Georgia).

Consumer Alliance Goals for July 2013 – July 2014:

- Implementation of the Affordable Care Act project created by consumers
 - Some consumers are currently working on medical food act within their states
- Transitioning project related to Sickle Cell Disease and PKU
 - Monthly meetings will be arranged
- Active involvement of consumers on all workgroups
- Increase consumer participation on monthly calls
 - Planning to increase consumer exposure during SERC/SERGG meetings

The following is an overview of the 2013-2014 goals:

Communication Strategy and Plan (POC: Jodi Kotrady-Hatin)

The Consumer Alliance now has a Facebook page. This widely used social media tool will be used to share important information and news with alliance members, the greater consumer community, industry partners, and related non-profit organizations. The Facebook page will be used in coordination with the southeastgenetics.org website, which is already a wonderful resource for learning about consumer activities across the region.



ACA Implementation:

The consumer alliance will also look for ways to raise awareness for newborn screening and individual genetic disorders within legislatures and across the general population. Consumers are tasked to create an ACA project that will help to inform and educate each state about how ACA will affect individuals within their state.

Medical Home and Transitioning:

The Transitioning workgroup is moving forward with developing transition as a two component process: Sickle Cell and PKU. The transitioning group will be doing an assessment of activities in both of these diseases on a regional basis. The overriding model is Ify Osunkwo's idea based on the South Eastern Collaborative REgional Transition (SECRET) model. The workgroup will try to develop assessment tools to determine success in both areas for the complete psychosocial outcome and satisfaction, but also develop data on medical outcome. Specifically, adherence to diet in youth and young adults past 18 years old in PKU and adherence to transfusion, iron chelation, and hydroxyurea in sickle cell disease. After the assessment, the workgroup will develop a manual and pilot the intervention. Once the workgroup determines an approach based on the assessment of our region, the workgroup will reach out to other regions to determine potential for collaboration in the two diseases.

Consumer Updates:

The alliance welcomed two new consumer representatives; Vail Brennan (NC, PKU Parent), and Rachel Long (AL, PKU parent). We are actively looking for new members to join us from North Carolina, Puerto Rico, and the Virgin Islands.

Kristen Vanags will be stepping down from chair and Melissa Perez will be the new chair.

The alliance will conduct conference calls every first Sunday of every month at 8pm. Additional calls will be held to support project work. Consumer members are also encouraged to participate with other SERC workgroups. The chair will work with SERC grant coordinators at Emory University to provide needed project management to support ongoing consumer activities.

Consumer Alliance Management:

(POC: Rani Singh, Lokie Harmond, Yetsa Adadevoh, Melissa Perez)

*Special thanks to **Rani Singh PhD (PI, Emory)**, **Sharon Romelczyk (Genetic Alliance)**, **Han Andersson MD** and **William Perry (EP Workgroup)**, **James Eckman MD** and **Alex Kemper MD (Transitioning and Medical Home Workgroup)**, **Kristen Smith (NBS Connect)**, and **Mary Rose Lane (Emory)**.*