SERC Consumer Alliance
Workgroup Report - August 28, 2012

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 community on grant activities and projects, and working on consumer alliance driven projects to benefit the NBS & Genetics 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 5th annual face-to-face at the 2012 SERGG/SERC Meeting from July 19th – 21st. 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, Babies First Test, and a brainstorming activity to create a list of consumer resources and needs. The alliance also had an opportunity to view a CCHD screening video and a medical foods video developed by Greater Good Communication in collaboration with consumers. Invited speakers and non-consumer participants also enriched the meeting.

Special thanks to Vaughn Edelson (Genetic Alliance), Han Anderson MD (Co-PI/EP Workgroup), William Perry (EP Workgroup), James Eckman MD (Transitioning/Sickle Cell Disease), Yetsa Adadevoh (NBS Connect), Rani Singh PhD (PI), Heather Ollison (BioMarin), Erica Stelten (BioMarin), Rita Underwood MD (Emory), Alana Aisthorpe (Emory), Mary Rose Lane (Emory), Jill Shugar (HRSA), Steven Humes (Regional Coordinator/Hemophilia), Ify Osunkwo MD (Sickle Cell Disease), and Alex Kemper MD (Medical Home).

The following consumers attended the 2012 annual meeting:

Valerie Williams (Alabama), Kristen Vanags (Georgia), Anna Parker (Georgia), Melissa Perez (Florida), Jodi Kotrady-Hatin (Florida), Mike Singletary (Louisiana), Kristy Tunnell (Mississippi), Sherry Burney (Tennessee)

Consumer Alliance Goals

August 2012 – July 2013

- Development and implementation of a consumer communication strategy
- Continued collaboration with the NBS Connect project team
- Renewed focus on expanding the number of disorders and states represented on the alliance.

A transition project related to Sickle Cell Disease has also been discussed. The following is an overview of the 2012-2013 goals:

Communication Strategy and Plan (POC: Kristen Vanags, Melissa Perez, KC Singletary)

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.

In addition to expanding our overall communication network, Melissa Perez (FL Consumer) and KC Singletary (LA Consumer) are spearheading a special communication project to disseminate emergency preparedness information to consumers. They will work closely with William Perry and Hans Anderson MD to ensure artifacts and content are consistent with current EP best practices. M. Perez and KC Singletary will update the alliance on progress during regular conference calls.

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.

**NBS Connect Collaboration (POC: Kristen Vanags)**

During 2011-2012, consumer alliance members provided valuable feedback to the NBS project coordinator during the user-testing phase. SERC consumers were excited to see NBS Connect launch shortly before the 2012 Annual Meeting. Over the next 12 months, the alliance will promote the use of this groundbreaking resource. Consumer members will also provide ongoing feedback to the project coordinator to support continuous improvement of NBS Connect.

**Consumer Alliance Membership (POC: Kristen Vanags)**

Leading up to the 2012 Annual Meeting the alliance welcomed three new consumer representatives, Sherry Burney (TN, PKU Parent), Valerie Williams (AL, SCD Parent, returning member), and Kristy Tunnell (MS, VLCADD Parent). In addition, Stephanie Harry (GA, LCHADD Parent) was added as a member in late August. S. Burney, V. Williams, K. Tunnell, and S. Harry are now connected to the alliance through the SERC Consumer Listserv. We are actively looking for new members to join us from North Carolina, Puerto Rico, and the Virgin Islands.

**Consumer Alliance Management**

(POC: Rani Singh, Rita Underwood, Mary Rose Lane, Kristen Vanags)

In addition to conducting an annual face-to-face meeting, the alliance will conduct conference calls every two months. 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.