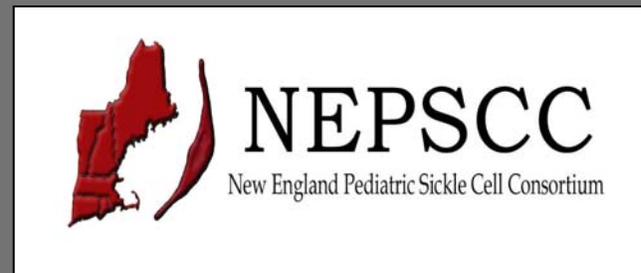


Surviving to Thriving:

Improving Long Term Outcome in Sickle Cell Disease

Held in the Colonnade Hotel, Boston MA September 16th 2010. Hosted by the New England Newborn Screening Hemoglobin Workgroup under the Auspices of the New England Newborn Screening Program and the New England Pediatric Sickle Cell Consortium.



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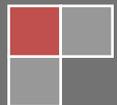


Table Number, Topic and Moderator	Issues Raised	Concrete Suggestions	Priority Issues and Action Steps*
<p>#1 Individual Data Collection and Usage</p> <p>Trish Kavanagh, BMC</p>	<p>a) Do not re-invent RuSH</p> <p>b) Need for our own data sets that would add more data including QoL academic and social issues</p> <p>c) Importance of identifying pcps and hematologists interested and willing to provide care to patients with SCD</p> <p>d) Constancy of care</p> <p>e) Track mortality</p>	<p>a) Work with RuSH and NENSP to interface efficiently</p> <p>b) Collect data annually on patients and include QoL and academics and social issues</p> <p>c) Create a list of PCPs and (adult) hematologists willing to provide SCD care</p> <p>d) Develop 'best practice guidelines'</p> <p>e) Develop a tracking system and list</p>	<p>1a) Attend upcoming CDC sponsored RuSH update in Atlanta (11/3-4 2010).*</p> <p>1b) NESPCC/NENSP note information from above, refine data tool and cont. collecting</p> <p>1c) Identify a point person in each institution to create a list, with contact information, of pediatric and adult hematologists, high risk Ob/gyn and PCPs interested in providing care to patients with SCD. Upload this information* onto the NENSP and NESPCC websites.</p> <p>1d) Refine existing NESPCC guidelines</p> <p>1e) Refine system based on NENSP and RuSH experiences</p>
<p>#2 National Data Collection</p> <p>Matt Heeney, Children's Hospital Boston</p>	<p>a) Issues around privacy</p> <p>b) Issues around duplication</p>	<p>a) Need to collect data in a private and sensitive way. Need to educate around SCD and the economic and health benefits of data collection.</p> <p>b) Careful data set development and sharing of tool(s)</p>	<p>2a) Need to create a work group to meet on a regular basis to work out how to collect LTFD for the NENSP that 'meshes' with RuSH, 1b) above.</p> <p>2b) Identify group members at this time. Start after the Nov. CDC meeting*</p>

*Denotes items (1a, 1c, 2b, 4b) that can be undertaken immediately

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<p>#3 Health Care Reform</p> <p>Naheed Usmani, UMass Memorial Medical Center</p>	<p>a) Basic Health Care needs are not met for the socially disadvantaged</p> <p>b) Massachusetts is trying in this arena but there is not the feed back to the providers and the consumers necessary for there to be knowledge in the community and then the power to try to enact appropriate changes.</p>	<p>a) Increase public health and provider awareness of changes and potential impact of changes</p> <p>b) Provide social and if possible psychological help to the families to give them a better chance at understanding the changes and their impact.</p> <p>c) Consortium should take on the responsibility of monitoring health care reform as it impacts our patients and share the information with the SCD community.</p> <p>d) Create a registry of primary care and specialists interested in caring for patients with SCD</p>	<p>3a) Work with DPHs to share and disseminate this information.</p> <p>b) Individual institutions' responsibilities at this time as unable to provide cross institution support (hard enough to provide own support!)</p> <p>3c) See 3a) above</p> <p>3d) See 1c) above</p>
<p>#4 Pediatric Screening Tests for Adult Providers</p> <p>Kate Stevens, Connecticut Children's Medical Center</p>	<p>a) TCD not required for adult providers!</p> <p>b) Crucial issues around the communication of transfusion issues</p> <p>c) Neuropsych. ...if only</p>	<p>a) Develop a health summary card or similar to allow detailed patient information to be available where-ever the patient is.</p>	<p>a) Develop a task force to work out how to do this efficiently and across centers of the consortium.</p> <p>iv) Work with AABB and own blood banks to determine what information to collect how and where. Develop a workgroup.</p>

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<p>#5 <i>Whose Responsibility is it?</i></p> <p>Julie Kim Dartmouth-Hitchcock Medical Center</p>	<p>a)Issues of medical home...who/where/does this need to be different in the SCD population than other populations?</p> <p>b)Logistical issues of providers...where/who/how far</p>	<p>a)Outreach education for the providers, PCPs, public, patients and parents</p> <p>b)Increasing Communication: MD check list, soc.service lists</p> <p>c) Need for stronger transition programs</p> <p>d) Develop list of providers</p>	<p>5a) At NEPSCC meeting discuss what information, what format, to whom. NEPSCC or small group to develop.</p> <p>5b) See 1c above</p> <p>5c) Ongoing project for Consortium: developing “ideal” transition program.</p> <p>5d) See 1c above</p>
<p>#6 <i>Pregnancy in SCD</i></p> <p>Joanna Luty, Baystate Medical Center</p>	<p>a)High Risk: who should be in charge?</p> <p>b) Transition: does pregnancy make you an adult?</p> <p>c) Post-natal planning</p> <p>d)Newborn/NICU/Pedi team(s)</p>	<p>a)Identify/create a network of pedi/adult HROB</p> <p>b)Clarify what transition means in this setting</p> <p>c) SW support for parenting issues. SW/OB for post natal planning</p> <p>d)Create an appropriate ‘baby’ team</p>	<p>6a) See 1c) above: Include High Risk OB/gyn on provider list</p> <p>6b) Part of 5c)</p> <p>6c) Part of 5c)</p> <p>6d) Work with NICU, newborn staff and pediatricians to develop guidelines for managing SCD in pregnancy.</p>

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<p>#7 Genetic Counseling</p> <p>Farzana Pashankar Yale</p>	<p>a) Need for SC trait counseling in teenage years</p> <p>b) Need for appropriate knowledge in PCP. Who should be involved in counseling the family with an abnormal Hb</p> <p>c) Need for handouts/printed material</p>	<p>a) Provide a mechanism for trait counseling in teenage years. At local high school?</p> <p>b) Each center providing care should have an identified counselor.</p> <p>c) Develop handouts culturally and language appropriate</p>	<p>7a) NEPSCC and NENSP to work with public school district to try to be given time to present to middle or high school classes.</p> <p>7b) Work with institution genetic division to have genetic counselor at clinic sessions</p> <p>7c) NEPSCC and NENSP to develop handouts culturally and language appropriate</p>
<p>#8 Guidelines for Transition from Childhood to Adulthood in SCD</p> <p>Maria Champigny, Boston Medical Center</p>	<p>a) At what age is transition appropriate?</p> <p>b) Need for all staff to be 'on the same page' with transitioning</p> <p>c) Parental involvement must be present.</p> <p>d) ? Move towards a model of family centered care</p> <p>e) Patients see heme doctors as primary care providers...must move away from this.</p>	<p>a) Understand different coping mechanisms in the teenagers</p> <p>b) Set expectations as to what/when/how transition.</p> <p>c) Develop a web based means of communication.</p>	<p>8a) part of 5c)</p> <p>8b) part of 5c)</p> <p>8c) Develop a web team to work on this and other web needs.</p> <p>8d) Part of 5c)</p> <p>8e) Part of 5c)</p>

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<p>#9 <i>Who is an Adult Anyway</i></p> <p>Mary Huang, Massachusetts General Hospital</p>	<p>a)Have to pay attention to hospital mandates</p> <p>b)Is a state of mind when able to make reasoned, rational decisions and hold responsibility for these.</p>	<p>a) Must pay attention to three concerns: -constancy -communication -expectations</p> <p>b)"Transition" when patient is responsible, has knowledge of illness, medicines, insurance, and displays a competency to being autonomous</p>	<p>9 a) Part of 5c)</p>
<p># 10 <i>Perspectives on SCD by Provider Type</i></p> <p>Cathy Rosenfield, Tufts New England Medical Center</p>	<p>a)Major concerns re trust and relationships</p> <p>b)Need for psychosocial support including Child Life SW and Psychology</p>	<p>a)Need guidelines in ER, and elsewhere for RN, MD, residents, SW</p> <p>b) Hold seminars for providers to increase knowledge.</p>	<p>10 a) NEPSCC to work on developing these at meetings, using work done by Kavanagh et al on Quality Indicators. Need to do similar work in adult world.</p> <p>10b) NEPSCC to work on.</p>

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