

Act 36 Education Work Group 2/11/09 Agenda

- Welcome and Introductions
- Review of meeting goals and structure (Landscape – Brainstorm – Craft)
 - What educational and training materials are needed for each stakeholder audience
 - Audiences:
 - Hospitals
 - Midwives
 - Family practice physicians/pediatricians
 - OB/GYN physicians
 - Treatment Centers / Specialists
 - Parents
 - Labs
 - Public / Media
 - DOH / Internal
 - What resources and training mechanisms currently exist
 - How can we interface with existing mechanisms
 - Educational needs feedback received from other 2 work groups
 - Brainstorm
 - “Parking Lot”
 - List of resources reviewed
- Discussion /review of existing resources /materials available for each stakeholder audience
 - Materials available
 - Dr. Vockley presentation
 - Act sheets / Fact sheets / links to existing resources
 - PerkinElmer materials
 - DOH link to parent Act sheet and DOH provider manuals and pamphlets
 - Material focus
 - Subject matter (22 supplemental conditions)
 - Process / protocols
- Lunch
- Brainstorm
 - What is needed for each audience
 - How can we interface with existing training mechanisms – point of contact, societies – creative ways to get information out
 - What is missing – doesn’t exist now but is needed
- Design educational materials for subject matter and process training needs
 - Identify best resources
 - Web based
 - CMEs
- Next Steps
 - What follow up interactions needed
 - Presentation to TAC in early March
- Travel Reimbursement
- Adjournment

PA DOH Education work group 2/11/09 meeting notes

- Audience:
 - Medical students / nursing students / healthcare professional students
 - Hospitals
 - Physicians
 - Nurses
 - Neonatal intensive care / NICU
 - NBS coordinators
 - ED/ER
 - Hospital clinics / satellite locations
 - Hospital lab
 - Dieticians
 - Social workers (children and youth)
 - Outpatient
 - All staff who connect with parents
 - Midwives (certified, professional, CRNP, lay, underground)
 - Treatment centers / metabolic specialists / genetic counselors
 - Prenatal physicians / OB/GYNs
 - Neonatologists on the front end – perinatologists (**pre-birth education/outreach is important**)
 - Community based ambulance services / transport
 - DPW, CHIP, Medicaid – all financial related resources
 - CRNP clinics
 - Schools / nurses
 - Other agencies – such as Dept of Education
 - DOH – internal, County/Muni state health centers, other DOH programs
 - Lamaze and breastfeeding programs and classes
 - Professional societies (CMEs)
 - Planned parenthood clinics
 - Teen homes for pregnant mothers
 - High school education – teen health ed
 - Colleges – clinics and health ed classes / professional health classes
 - Parents / extended families / grandparents
 - Media / social marketing / outreach advocacy / TV commercials / Internet
 - Churches
 - Adoption centers / social and case workers

- Issues
 - Cultural and language differences / diversity / translators
 - Brochure with filter paper packet has 2 sentences per disease in Spanish
 - Add press / communication to work group
 - HAP: Einstein, Temple and Reading hospitals have excellent cultural communication programs in place – get materials from them
 - HAP just did study on top 5 languages in PA: include Russian, Chinese, Spanish and Vietnamese (get from HAP)
 - End of February, HRSA Inheritable Disease committee meeting – get from them list of proposed new conditions for testing (other than MS/MS) – e.g., Krabbe – what’s on the horizon?
 - Create an excel spreadsheet with web based information

- Resources:

- Step One booklet from PerkinElmer – same information as on condition sheets faxed from lab with results
 - DOH NBS brochure – must modify to add new conditions / for general public and parent use; add list of treatment centers to brochure
 - DOH Provider Manuals – for healthcare professionals; baseline education tool; distributed to:
 - NBS coordinators
 - Family Practices / Pediatricians
 - Midwives
 - Metabolic treatment centers
 - Community health centers
 - DOH NBS website (new url – simplified: www.health.state.pa.us/newbornscreening)
 - Need to link all materials
 - for parents, providers and general public
 - ACMG ACT sheets for physicians and medical students
 - UMass Fact sheets – faxed to HCP and NBS coordinator
 - NY state Fact sheet – one pager, for HCP/physician
 - Genetics Home Reference – US Govt, for educated general public
 - PerkinElmer Fact sheet – faxed to HCP/physician and available on web site
 - HRSA Star-G Genetics Fact sheet for parents (link from DOH website)
 - Need to create an excel spreadsheet list of all resources, to include the following categories (similar to what HAP has created – they will share/draft):
 - Targeted audience
 - Resource Materials
 - Distribution time frame (pre or post birth)
 - Distribution location
 - Format (web /hard copy, newsletters, pamphlets)
 - Languages available
 - Literacy level
 - Ways to reach audience
 - Dr. Vockley’s Tandem NBS chart, as a DOH staff resource
 - Providers need to know algorithms
 - Education needed to Ped/FCP regarding recommendations
- Ways to get information out:
 - Parent advocacy groups – website, listservs
 - AAP
 - Web based training module with Univ. of Pitt provides CMEs
 - Physician based
 - Expand to nursing based
 - Public Health Initiatives / Academy of Family Physicians
 - Monthly e-newsletters
 - Bi-monthly e-magazine
 - Regional conferences / clinical education series
 - CME webcasts – live webinars, digitally recorded
 - State licensure – list servs
 - Clinic for Special Children – CME course integrating clinics into medical home and with midwives
 - Ground round presentations at hospitals
 - Hospital dept. meetings
 - Newborn screening coordinator meetings
 - MOD
 - AHEC (Area health education centers) – provide curriculum and credits for primary care education

- March of Dimes
 - Save Babies
 - Other Dept programs, such as breastfeeding
 - Association of pre-natal educators
 - Lactation association
 - Breastfeeding coalition
 - Advanced Nursing Publication (free)
 - Health System – newsletters, website
 - Insurance Cos – newsletters, websites
 - PEBTF
 - Hospital newsletters, website
 - Local newspapers
 - On hold message for doctors offices (create one)
 - PSAs (public service announcements)
 - In hospital public service education
 - DOH & Commonwealth – SEAP, WIC – SWAN
 - Look for sponsorship by advocacy groups and retail stores
 - Posters to reach public, especially underserved populations – where do they go?
 - Doctors offices
 - Grocery stores
 - Health food stores
 - Hospital elevators
 - Buses / public education
 - Retail outlets, especially if have clinic
 - Formula companies (limitations at hospitals) – target families
 - Media
 - Health Fairs / Safety days
 - Human Resource depts. of companies
 - Call center for state – “Did you know....”
 - Develop DVD, similar to hearing screening – competency based training, with credits available by hospital
 - Specific Health Care groups – identify how they communicate – list serves
 - Midwives – get contacts from HAP
- Educational Needs from Initial Follow-up process work group:
 - Educate physician centers – clarify responsibility of physician or PCP on the filter paper
 - Pre-natal education – importance of correct contact information
 - Education for nurses – labeling of screening (metabolic & genetic screening vs. “PKU”)
 - Medical screening education
 - Understanding the difference between repeat filter screen and confirmatory testing
 - Competency of blood spot collection
 - Education on the completion/collection of filter paper, including transportation requirements to labs (how to get to UPS/preventing delays)
 - Education Needs for Hospital staff:
 - DOH mandates / best practices
 - DOH Hospital facility regs
 - DOH hospital requirements related to physician orders
 - Joint Commission (Sharon at HAP has done pieces on this)
 - DOH and HAP to collaborate to put together a chart using HAP’s suggested format
 - Parking Lot
 - Gap in coverage for newborns that are MA covered but not born to MA moms
 - Long term training – connect with current training and mechanisms

- Transportation issues
- Get from HRSA proposed new conditions
- Next steps:
 - This education work group and process will take longer than one month
 - Need to ID immediate education/communication needs vs. longer term/ongoing needs, recognizing there are 2 aspects to educational needs:
 - Subject matter (conditions, general public awareness)
 - Process and protocols for expanding DOH follow-up and for best practice
 - Focus is to:
 - understand the resources currently available
 - what materials do we want to pull into our outreach/education (pamphlet, provider manual, website)
 - what do we need to develop
 - DOH will type up meeting notes and share with current participants and those who were unable to participate in meeting
 - DOH will invite additional participants, to assure all perspectives heard, including parents (get names from Dr. Renee Turchi), PCP/pediatricians, UMass, communication & Lisette Cortes from DOH, treatment centers, and additional hospital representation (ask Sharon/HAP for outreach to them)
 - DOH and HAP will work together to draft excel resource spreadsheet
 - Teleconference will be arranged for 2/19 from 2-3:30 to review resource charts and NBS pamphlet, which has a time sensitivity (revised post meeting to 2/26/09)
 - Follow up face to face meeting will be arranged for Wed, 3/11 from 10 am – 3 pm, to continue this discussion
 - Follow up with Dr. Melvin at St. Christopher's, as Melita Jordan has asked him to help us create a web based training

Summary of NBS Work Groups' educational needs recommendations:

Educational Needs from Initial Follow-up process work group:

- Desire for recommended uniform process guidelines/ best practices to be shared with hospitals, especially as to filter paper process and finding babies/parents
- Educate physician centers – clarify responsibility of physician or PCP on the filter paper
- Pre-natal education – importance of correct contact information
- Education for nurses – labeling of screening (metabolic & genetic screening vs. “PKU”)
- Medical screening education
- Understanding the difference between repeat filter screen and confirmatory testing
- Competency of blood spot collection
- Education on the completion/collection of filter paper, including transportation requirements to labs (how to get to UPS/preventing delays)

Education Needs for Hospital staff from 2/11/09 education work group:

- DOH mandates / best practices
- DOH Hospital facility regulations
- DOH hospital requirements related to physician orders
- Joint Commission (Sharon at HAP has done pieces on this)
- DOH and HAP to collaborate to put together a chart using HAP's suggested format
- Need to ID immediate education/communication needs vs. longer term/ongoing needs, recognizing there are 2 aspects to educational needs:
 - Subject matter (conditions, general public awareness)
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- Focus is to:
 - understand the resources currently available
 - what materials do we want to pull into our outreach/education (pamphlet, provider manual, website)
 - what do we need to develop
- Need to finalize NBS pamphlet, which has a time sensitivity
- Follow up with Dr. Melvin at St. Christopher's, to explore Melita Jordan's discussion with him about helping us create a web based training

Education needs from 2/12/09 referral/medical home work group:

- Physicians need to understand recommendation of repeat versus referral (timing of repeats, especially with CF)
- Physicians should send to accredited CF centers for sweat tests
- Giving physicians clear recommendations – language DOH staff should use when speaking with PCPs/pediatricians
- Referrals after first positive/repeat to treatment center is important
- DOH should play a primary role in communication and protocol establishment
 - To hospitals and physicians for first contact
 - Understanding what the calls mean and what to do with it
 - Contact with treatment centers
 - Treatment centers should not cold call patients – PCP should contact parent first
- DOH should focus on data collection
 - Web based data entry and access
 - Treatment center access to the data, for treatment center QA and process improvement at treatment level
 - Access to data in real time
 - PA to plug into national networks on NBS (e.g. Dr. Rinaldo)
- DOH should play a primary role in communication process

- Data entered for every treatment
- Protocols for contacting parents
- Protocols for contacting treatment centers
- Track timelines for notifications
 - DOH → person responsible for baby
 - Lab → person responsible for baby and DOH
- What other tools and mechanism needed to share care of child
 - Create a directory / database, by geographic area, by condition
 - What kind of clearinghouse do we need
- Accredited CF centers have a good referral process/system (might be a good model/pilot), which meets standard of care – issue is getting to them timely
 - List of CF centers by zip codes they handle – which center is closest to where child lives
 - State sanctioned treatment centers by condition
 - Contact with PCP – treatment center near where child lives

Summary of recommendations/comments from 3/11/09 education work group meeting:

- Reviewed and approved NBS brochure with recommended changes
- For Resource charts, consensus to modify numbering with alphabetical letter and numbering; maintain summary chart with color in heading line only; maintain English version by targeted audience
- Don't reinvent the wheel - use existing materials - OK to use MD provider materials to update our provider manual, with review by our TAC/treatment center specialists
- Use ACMG materials as our external reference link (provide only one link)
- We should coordinate our condition information/manual so it is consistent with the information the labs are faxing to submitters/physicians with the test results
- Agree that we should coordinate lab result reports with the same instructional language for physicians, to include key reminders for parent guidance, and what to do regarding need for repeat or immediate referral
- Create posters for physicians offices (and future public venues)
- Create a laminated/quick guide for parents to review at physician offices
- Need to have outreach to migrant families
- Reviewed the hot off the presses (not published yet) cards created by NYMAC for parents that give a quick summary of the disease and the metabolic contact information, for parents to give to hospitals. Per Dr. Trish Gordon, treatment centers give parents a letter that they can give to ER regarding the condition - we should get those and be consistent with our information
- Educational priority needs for parents: subject matter/conditions and the value of testing
 - target birth educators at hospitals, midwives and pre-natal outreach, OB/GYNs, health centers, pre-natal classes - use March of Dimes video at birthing classes
- Educational priority needs for physicians: subject matter and process
 - best way to reach physicians is through association newsletters and free web-based CME training
 - 3 key training focus areas are:
 - what is involved in expanded newborn screening & follow-up
 - what is the process: who contacts whom - how do they get results
 - what immediate action is required - what should a physician say/share with caregivers/parents when notified of abnormal result
- For lay midwives, need to provide them with best practice/value for getting the supplemental testing; get the opinion/quote of Dr. Holmes Morton for our midwives material
- Update the provider manual - focus on adding the new conditions and information that gets the PCP to a treatment center; include common symptoms, what they should tell the parents. Distribute a hard copy to every OB/GYN, FP and Pediatrician practice in the state.
- Need to ascertain how many languages we really need for outreach materials: issue of dual languages in home versus on speaking a foreign language

- check with Philadelphia and Allegheny depts. of health and our DOH district offices, and Bob Wise for PE (for lab report language) to ascertain what direct care language needs they have
- Best practice to assure that hospitals and birth centers actually provide the Spanish brochure to Spanish speaking mothers
- Use the March of Dimes video for parents - see if the hospitals will show it to the parents (if not already)
- Agreed that our proposal to create a video for a web based physician training was the best way to proceed for this audience - which can be put on our web site