

MEETING SUMMARY

Working Together for Premature Infant Health: RSV Patient Advocacy Ad Board

Friday, April 21, 2017

Driving Greater Awareness & Access for Premature Infants

RSV is a significant burden on the community and premature infants remain a vulnerable population. New data shows that for some at-risk premature infants, not having access to RSV prophylaxis can increase the risk of hospitalization and drive greater cost to the healthcare system. Multi-disciplinary stakeholders were brought together to provide insight exchange and current perspectives related to:

- challenges accessing RSV prophylaxis and the impact on healthcare providers and families
- opportunities to address access barriers
- updated data sets specific to RSV prophylaxis
- RSV awareness gaps and opportunities to elevate awareness among parents and providers

Challenges & Opportunities Identified

Challenges specific to RSV awareness and access to RSV prophylaxis remain, but through continued engagement stakeholders are collaborating on the development of new ideas and tools for activation.

Parent and Provider Education: Parents and providers alike are not informing or informed of RSV as widely needed.

- Greater information sharing and education about RSV and data specific to RSV prophylaxis is needed especially among pediatricians.
- Parent education is always needed as new parents face prematurity every day. Consider how to educate further “upstream” when parents know they will deliver early.
- Great RSV education tools exist, continue to find ways to distribute and share among stakeholders.

Access: Advocating for RSV prophylaxis continues to be a burden.

- Need for more education on handling appeals process.
- Stakeholders working to inform AAP and payers of new data for consideration and bring multi-disciplinary stakeholder viewpoints forward as COID policy is evaluated.

RSV Awareness: Development of RSV Awareness month and the Little Lungs campaign

- Engage around awareness month much earlier in the process with a strategic approach and tactical plan.
- Opportunities to develop and integrate new ideas and promote the Little Lungs campaign.

MEETING PARTICIPANTS

- Claire Brown, Hand to Hold
- JaNeen Cross, National Assoc. of Perinatal Social Workers
- Jennifer Degl, Morgan Learly Vaughan Fund
- Deborah Discenza, PreemieWorld
- Denise Ellison, National Assoc. of Pediatric Nurse Practitioners
- Mitch Goldstein, National Coalition for Infant Health
- Susan Hepworth, National Coalition for Infant Health
- Sally Schoessler, Allergy and Asthma Network
- Vincent Smith, National Perinatal Association
- Suzanne Staebler, National Assoc. of Neonatal Nurses
- Michel Young, National Medical Association

PROPOSED NEXT STEPS:

Information & Resource Sharing

- Provide updated data and educational resources as they become available
- Disseminate information and tools more broadly among stakeholders

Advocacy Tools

- Work with stakeholders to develop turnkey advocacy tools for parents and providers
- Connect key advocates to AZ subject-matter experts relative to CMS

Little Lungs/ RSV Awareness Month

- Identify additional tactics to create a Little Lungs 2.0
- Develop RSV Awareness plan and work with stakeholders earlier to coordinate and pull through