Overview of the Health Care Guidelines for Spina Bifida Across the Lifespan

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Chair, Professional Advisory Council at SBA
Associate Medical Director for Adult Care at SBA
Disclosures

• No conflicts of interest to report.

• This project is supported by:
  • The Spina Bifida Association
  • Spina Bifida Collaborative Care Network
  • The Centers for Disease Control and Prevention
Guidelines for Spina Bifida Health Care Services

- Prior guidelines published in 2006
Overview of the New Guidelines

• 2014 -- SBA and CDC convened steering committee as part of SBCCN
• Concluded an update and expansion needed
• 9 new topic areas suggested:
Oversight

• Medical Director
  • Tim Brei

• Steering Committee Co-Chairs
  • Pat Beierwaltes
  • Brad Dicianno
  • Nienke Dosa

• Executive Committee
  • Sara Struwe
  • Judy Thibideau
  • Julie Bolen
  • Adrienne Griffin
  • Lisa Raman
  • Jerome Chelliah

• 24 Working Group Chairs
  • Working Group members

• CDC Staff

• SBA Staff and Students
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<td>Organization of Workgroups</td>
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<td>Organizing Conference Calls</td>
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<td>April 1, 2016 – April 15, 2016</td>
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Methodology

• Recognized consensus-building methodologies for the development of clinical practice guidelines
  • Single Text Procedure
  • Nominal Group Technique
• More than 80 experts participated in the process
• Multi-disciplinary groups
• Spans newborn to adult
Format of New Healthcare Guidelines Document

• Outcomes – what we wish to achieve with good care
• Clinical questions – important questions that were targets of the literature review
• Guidelines – recommendations for care that are based on the literature review and clinical consensus
  • Metrics for good care
• Research gaps – important topics where research and clinical consensus are lacking
  • Synergistic areas with NSBPR
Conclusions

• Encourages evidence- and consensus-based practices
• Published and disseminated to the SB community
• Goal to optimize outcomes and improve care for all people living with SB
References


