

Improving genetic counseling access for parents of newborns who screen positive for cystic fibrosis: consensus guidelines

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Abstract

Introduction A risk associated with cystic fibrosis newborn screening (CFNBS) is parental misunderstanding of genetic information generated by the over 6,600 positive screens reported annually in the US. CFNBS algorithms incorporating DNA analysis can generate genetic information that requires clinical interpretation and has significance for the newborn, parents, and other relatives. Engagement between CF care centers and trained genetic counseling providers, such as licensed and/or certified genetic counselors (GCs), is variable and limited in providing information to CFNBS positive (CFNBS+) families. **Methods** Using a modified Delphi process, a workgroup of CF experts developed recommendations for engagement of genetic counseling services in CF care centers where CFNBS+ diagnostic evaluations are performed. Statements were assessed over three rounds of surveys, one face-to-face meeting, and through public feedback. **Results** Seventeen statements achieved >80% consensus (range: 82-100%). The workgroup affirmed prior CFF policy statements recommending genetic counseling for parents of infants with CFNBS+. The remaining statements addressed infrastructure and logistics of genetic counseling services, including defining appropriate training for genetic counseling providers and counseling content, establishing a path to equal access to genetic counseling providers across CF care centers, and setting a standard for client-centered CFNBS genetic counseling that is respectful of diverse patient needs and autonomy. **Conclusions** Implementation of client-centered genetic counseling for CFNBS+ families in CF care centers by providers with expertise in both CF and genetic counseling will require efforts to further define core concepts, enhance education of providers, and develop opportunities for access via telemedicine.

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