

**Conclusions:** Results suggest that the CF Foundation’s new web pages related to NBS are achieving the intended outcomes for most parents. Additional minor revisions may further enhance the quality of the web pages.

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**Table: Web Page Usage in 2012**

Specific Web Page	January	February	March	April	May	June	July	August	September	October	November	December	Average
Main NBS Page	2390	2712	2823	2793	2574	2205	2098	2394	2483	3169	2886	2376	2575
Screening for CF	1189	1254	1327	1241	1047	925	961	1098	1201	1426	1236	1071	1165
Sweat Test	900	1032	1080	1195	1070	1043	926	1032	1070	1383	1185	1039	1079
NBS Basics	949	1037	1089	1066	922	797	762	863	934	1277	1070	884	970
What is CF?	649	698	705	672	642	566	547	521	564	691	647	534	620
Understanding Results	593	657	622	582	587	532	556	592	629	763	655	585	613
Carriers of CF	586	631	587	555	488	419	424	468	510	655	524	451	524

CF, cystic fibrosis; NBS, newborn screening

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### SCARY STUFF: PARENTS’ SELF-SEEKING OF INFORMATION VIA THE INTERNET FOLLOWING THEIR CHILD’S DIAGNOSIS WITH CYSTIC FIBROSIS

Jessup, M.<sup>1</sup>; Shields, L.<sup>2</sup>; Branch-Smith, C.<sup>3</sup>; Douglas, T.<sup>3</sup> 1. *The Prince Charles Hospital/Australian Catholic University, Brisbane, QLD, Australia*; 2. *James Cook University/Townsville Hospital and Health District, Townsville, QLD, Australia*; 3. *Telethon Institute for Child Health Research, Perth, WA, Australia*

**Objective:** To explicate the information seeking behaviours of parents of an infant diagnosed with CF.

**Background:** The diagnosis of their child with cystic fibrosis (CF) is a devastating event compounded for most parents by CF being a hitherto unknown entity. Information and education are vital to their processing what is CF, its implications for their child and family, and their efficacious engagement with care. While health carers may plan a metered presentation of information and education, parents reportedly pursue further facts for themselves as they seek to process their child’s redefined health status.

**Method:** This qualitative inquiry was conducted to inform the development of a national survey of parent information needs beyond newborn screening (NBS). Semi-structured interviews were conducted with parents (n=10) of infants aged from 1 to 3 years diagnosed with CF following NBS. Interviews were recorded, transcribed and thematically analysed.

**Results:** Following diagnosis, participants reported embarking on a quest to find out all they could about this disease, which some had heard but had little reliable integral knowledge. Their pursuit was born of a desire to “get everything we could” and “to know the answers.” There was also a desire to supplement formal hospital literature, described as outdated, and a need to do their own searching. However, the internet gave them access to often unregulated information for which novice parents had neither the ability nor insight to discern the relevance or reliability of, despite trying to “stick to reputable websites.” Many reported resultant negative feelings coupled with a sense of information overload, particularly when first confronted with statistical and lifespan predictions, or emotive pictorial depictions. Several participants conveyed regret; “backing away” from accessing non-interactive, unsupported sources of information, which for some had engendered fear, summarised by one participant as “scary stuff.”

**Findings:** Imparting information to parents, especially in the initial diagnostic phase, will always be a process of balancing need-to-know with measured timing and context.

Findings from this study can equip CF care teams with insight into the art of balancing information and guiding parents, who are likely to access the relatively unregulated world of the internet. Maintenance of currency in official websites and a user-friendly perspective regarding content and its display is also recommended.

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### SPITTS: A NOVEL TEACHING STRATEGY FOR USE IN THE CYSTIC FIBROSIS CLINIC

Bendiak, G.N. 1. *Pediatrics, Alberta Children’s Hospital, Calgary, AB, Canada*; 2. *Faculty of Medicine, University of Calgary, Calgary, AB, Canada*

**Background:** The ambulatory care setting is often unpredictable, with caregivers striving to provide optimal patient care while under significant time pressure. In the cystic fibrosis (CF) clinic, these issues are frequently amplified, due to the multiple care providers vying for patient time, in limited clinic space. Given these issues, clinical teachers may find it challenging to integrate medical learners into their practice, and may not involve the multi-disciplinary (MD) team in the teaching of medical learners.

**Objective:** The goal of this project was to identify a model for teaching medical learners in the CF clinic setting, which could take advantage of the knowledge and experience of the MD team, while maintaining efficiency in the clinic.

**Methods:** A literature review was performed in order to identify existing models for efficient teaching in the ambulatory care setting. Existing methods were then adapted and modified, and a novel teaching strategy was developed which was tailored to the specific needs and strengths of the MD CF clinic. Social constructivist theory was used as the pedagogical grounding for this revised model.

**Results:** Five major models for teaching in the ambulatory care setting were identified. These included the Traditional Preceptor Model, Clinical Teaching Scripts, Teaching in the Patient’s Presence, One Minute Preceptor, and the SNAPPS model. These techniques use the established process of patient case review as a structured opportunity for teaching medical learners. Although several of these have been demonstrated to improve efficiency in teaching in the ambulatory care setting, none address the unique MD context of the CF clinic. Therefore, a novel method for case review in the CF clinic was created, the SPITTS Strategy:

- S – Summarize briefly the history and findings
- P – Problem identification
- I – Interview MD team
- T – Talk about the plan for patient management
- T – Teach a general principle
- S – Select an issue for self-directed learning

**Conclusions:** This is the first teaching model which has been developed for use in the ambulatory care clinic setting which specifically engages the MD team in the process of teaching medical learners. Adoption of this model may allow for an enhanced educational experience for medical learners in the CF clinic, while maintaining efficiency. Further assessment of these outcomes during the implementation phase will be required.

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### SEXUAL HEALTH: WHAT DO ADOLESCENTS KNOW?

Brown, J.<sup>1</sup>; Britton, L.<sup>1</sup>; Mims, C.<sup>1</sup>; Self, S.<sup>2</sup>; Troxler, B.<sup>2,1</sup> 1. *Pulmonary Division, Children’s of Alabama, Birmingham, AL, USA*; 2. *Pediatrics, University of Alabama at Birmingham, Birmingham, AL, USA*

**Background:** Knowledge deficits related to sexual health exist among adolescents with cystic fibrosis. Research has shown a clear lack of sexual and reproductive health knowledge among female patients with CF (1). Knowledge contributes to behavioral capability and is therefore a part of the framework of behavioral requirements for self-management. Research has demonstrated positive responses to age-appropriate educational opportunities with a sound theoretical base (2).

**Aim:** The aim of this study is to determine if education utilizing a sexual health teaching tool improves the knowledge of adolescents regarding sexual health.

**Method:** This project is a one group pre-test/post-test design. A knowledge survey was completed as a pilot to assess knowledge deficits among adolescents 14-21 years old. The survey questions addressed the definition