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Cystic Fibrosis Research News

Title:

Real life practice of sweat testing in Europe

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What was your research question?

This initiative of the European CF Society (ECFS) Diagnostic Network Working Group is aiming to better understand and improve current sweat test practices in European countries.

Why is this important?

People with cystic fibrosis (CF) have a high concentration of salt in their sweat and measuring this (the sweat test) has a key role in diagnosing CF. Even with the emergence of genetic testing, measuring sweat salt is still critical in making a diagnosis and it is essential that this test is done carefully and reliably. Results from different national CF registries in Europe demonstrate that a significant number of patients with CF have either missing sweat test documentation or misdiagnosis of CF as a result of improper performance and interpretation of sweat tests.

What did you do?

Using Working Groups established by the ECFS, we undertook a comprehensive and widespread survey of current sweat test practice across Europe. The survey was comprised of 66 items covering six areas; 1) CF centre/laboratory details, 2) information provided to patient/parent/carers, 3) the method of sweat stimulation, 4) the method of sweat collection, 5) sweat analysis and 6) processing of the result.

What did you find?

The survey was completed by 136 European sites across 29 countries. We identified evidence of good practice in many centres (e.g., high rate of centres participating in an external quality assurance scheme, and regular national sweat test auditing), but also considerable variance in the testing approach (sweat stimulation and collection), interpretation of results, and how the result is communicated. Most notably, we identified centres that were not using internationally agreed upon cut-off levels for sweat chloride concentration. We identified centres that deviated from US guidelines, which stipulate that sweat is stimulated and tested from two different skin areas. Cost is also becoming an issue for many centres.

What does this mean and reasons for caution?

Maintaining high quality sweat test services is a challenge in Europe, particularly with expanding newborn screening and costs relating to replacing equipment used for the sweat test that has becoming obsolete. An important limitation of the survey design was represented by the same values for various categories in 3/66 answers (sweat test cost and reimbursement, sweat collection time) that was confusing for respondents.

What's next?

The results highlight the need for training and educational resources, which the ECFS Diagnostic Network Working Group is now developing. In addition, the team is exploring the factors that may predispose to centres not following available guidelines, and how targeted support can be applied to improve quality.

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