### **RESEARCH HIGHLIGHTS**

### IN THIS ISSUE

# Public attitudes toward CF carrier screening generally positive

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The public accepts the idea of genetic testing to determine their cystic fibrosis (CF) carrier status, according to a systematic review of the related academic literature. The review, which covers 23 years of research, also shows that fears that a positive test result might cause psychological harm haven't been borne out. After analyzing the results of all 85 studies on carrier screening published since the discovery of the CF transmembrane conductance regulator (*CFTR*) gene,



the Australian research team could find no barriers to making population-based screening a routine part of health care. The conclusion is timely because the UK National Screening Committee is currently reviewing its policy on screening for CF carrier status during pregnancy. Screening is offered in the United States and Australia, but, the authors note, in the United Kingdom, Canada, and France, population-based CF carrier screening is not currently recommended and is generally offered only to those who have a family history of CF and to partners of individuals with CF. In addition, the study found that individuals are most likely to be tested in a prenatal setting and, if they are found to be a carrier, are generally willing to inform family members and relatives of the increased risk. Those who receive a positive test result correctly recall and understand their carrier status. When asked, most would prefer a direct offer of testing rather than a passive offer. There was, however, some misunderstanding about the possibility of risk despite a negative test result, given that CF carrier screening is only 80% accurate among northern Europeans. —Karyn Hede, News Editor

# Can we afford personalized genomic tests?

#### see pages 225 and 251

As health-care costs continue their upward spiral, attention has turned to the cost-effectiveness of treatments. The role of genomic testing in medical care is still a matter of debate, with health economists and policymakers



beginning to insist that new treatments make economic sense in addition to clinical sense. Phillips et al. reviewed cost-utility analyses for 59 published studies in the comprehensive Tufts Cost-Effectiveness Analysis Registry. They report that many clinical genomic tests—what the authors call personalizedmedicine tests—have not been evaluated for cost-effectiveness. Of those that have been tested, about 20% are cost-saving; most (72%) provide health benefits but at a higher cost. The remaining tests were deemed costly without providing any health benefit. The authors also identify gaps in the data collected for new genomic tests and suggest that the National Institutes of Health Genetic Testing Registry could be expanded to include measures of affordability and cost. Moreover, they call for prioritization of genomic testing so that newly developed tests prove not only their clinical utility but also their economic value. In an accompanying invited Commentary, Grosse et al. question the need for cost-effectiveness studies before clinical effectiveness has been shown. Instead, they advocate risk-benefit modeling, which they argue could yield the clinical information needed to better inform evidence-based decisions regarding clinical utility. Clearly, however the evaluation is made, affordability will be part of the equation in determining the place genomic testing will earn in medical practice. — Karyn Hede, News Editor

### **NEWS BRIEFS**

## More support for genetic origins of political beliefs

A new twin study adds to the growing evidence that genetic predisposition contributes to our political leanings. The report, published in *Political Psychology*, provides empirical evidence of this, although the authors are quick to point out that the study does not suggest that genes are the sole determinant of our views. The findings are based on the results of a survey designed explicitly to tease out personality traits and political attitudes among nearly 1,200 sets of middle-aged twins—

both identical and fraternal—identified through the Minnesota Twin Registry. The identical twins' political views were consistently more similar than those of the fraternal twins; even after controlling for a common environment, the genetic association remained significant. The research team found that the genetically influenced personality characteristic defined as "openness" tended to be correlated with a liberal orientation, and, to a lesser degree, "conscientiousness" was associated with conservativeness. Of course, the authors are careful to note that environmental factors, as well, "exert influence

throughout the lifespan." Their results also suggest that political predispositions are not linked to personality traits such as extraversion or neuroticism but "may constitute another dimension of personality." —Karyn Hede, News Editor

## Pitfalls of the "wild frontier" of high-throughput genomics

Data, data everywhere, but no time to stop and think about it. That's one of the many pitfalls that can beset the unprepared in the wild frontier of modern genomics. But stop and think we must if

#### RESEARCH HIGHLIGHTS

### NEWS BRIEFS (continued)

we are to make sense of the high volume of data generated by genomic studies. In a feature recently published in *PLOS Biology*, a team of genomics researchers uses caricatures to categorize counterproductive behaviors they have seen among genomics researchers. Along with laughs, the authors provide recommendations for experimental design, effective communication among group members, and sound interpretation of data. Two of the six types are shown here (illustrations by Dan Madsen). —*Karyn Hede, News Editor* 



The "farmer" builds a vast storehouse of genomic data but falls short on experimental design.



The "gold miner" keeps digging until a "significant" result surfaces.

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- Original reports which enhance the knowledge and practice of medical genetics
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As the official journal of the American College of Medical Genetics and Genomics (ACMG), the journal will:

- Provide a forum for discussion, debate and innovation concerning the changing and expanding role of medical genetics within the broader context of medicine
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Finally, as genetics becomes increasingly important in the wider medical arena, we will be an accessible and authoritative resource for the dissemination of medical genetic knowledge to providers outside of the genetics community through appropriate reviews, discussions, recommendations and guidelines.