

Genetics Education for Physicians: Lessons Learned (some the hard way)

NHGRI

Inter-Society Coordinating Committee

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I hope to accomplish the following:

- Share some observations based on 10 years' experience
- Suggest some questions to guide your efforts
- Update you on the status of NCHPEG

A Partial Summary of NCHPEG's Experiences

Preparing health professionals for individualized medicine. McInerney JD, Edelman E, Nissen T, Reed K, Scott J. *Personalized Medicine* 9(5): 529-537, 2012.

Some Observations

- Different specialties really think they are different (and special).
- Genetic contributions to disease are not always obvious to non-geneticists (the AAFP experience).
- Language can introduce unintended barriers.
 - “genetic diseases” & “genetic disorders”
 - a “niche” for medical genetics
- Motivations differ by setting.
 - Undergraduate medical education
 - Education for practicing physicians

Central Questions

- Which content is appropriate?
 - Accurate vs. complete – not necessarily the same
- Who needs to know what?
- Which clinical behaviors and attitudes do we want to change, and can we?
- How do we define and measure success?
 - Ask and answer this question up front, not halfway through the project. Have the evaluation specialist(s) involved from day one.

Roles for Clinical Geneticists

- *Longitudinal care*: working with “conditions that cut across disciplinary boundaries and have a prominent genetic basis, e.g., DS or NF”
- *Consultative care*: “geneticist is not the primary caretaker, but plays a critical role in guiding differential dx, genetic testing, counseling”
- *Genomic testing*: a focus on “risk assessment and management of common disorders...a critical aspect of the future of (genetic medicine)”

Korf BR. 2010. From the president. *The ACMG Medical Geneticist* 5(2):1,7.

Roles for Clinical Geneticists

How do we prepare non-geneticists to intersect with these roles?

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NCHPEG and Jackson Laboratory

- Jackson Laboratory is building a program to provide healthcare provider education in genomics
- JAX reached out to NCHPEG with news of closure
 - NCHPEG educational staff are JAX employees as of September 3 (Kate Reed, Emily Edelman, Therese Nissen)
 - Finalizing discussion with NCHPEG for permanent home for the website and legacy educational programs with the intent to continue to make these programs freely available to the community
 - Plans for new programs under development
- Contact: Dr. Thomas Litwin, Vice President of Education
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