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

NHGRI

Inter-Society Coordinating Committee

19 September 2013
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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

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)”

Roles for Clinical Geneticists

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

- **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”
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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
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