




NCC Collaborator

Expanding Genetic and NBS Services Through Multifaceted Partnerships



The Art and Science of Genetic Information

Just as the information carried within our genes has a pervasive impact on cells and organs and on human health and disease, information about genetics has the potential to transform the way healthcare providers, the public health community, and the patients and families they serve think about health. There is both an art and a science to the effective interpretation and communication of genetic information to healthcare professionals and the public, as well as to the translation of new genomic discoveries into healthcare delivery.

Since their inception in 2004, the HRSA Genetics Collaboratives (RCs) have been deeply committed to improving access to genetic information by bringing together the genetic services, primary care, newborn screening, and public health communities. Some RCs have focused on enhancing the use (and usefulness) of family histories by both providers and families, others on finding novel ways to deliver genetics education to primary care providers, and others on infusing

genetic thinking and sensitivity into the concept and practice of “medical home.”

In this issue of the *NCC Collaborator* you will read about exciting RC plans, activities and accomplishments that apply the art of making genetic science accessible to primary care providers and families. On the next page, Dr. Greg Feero, Special Advisor to the Director, National Human Genome Research Institute (NIH), describes a stimulating national dialogue now underway around primary care education in genomic medicine that promises to catalyze the work of the RCs. In fact, the NCC/RC system is already collecting evidence of the improved health outcomes that result from artful communication to and scientific application of genetic information by primary care providers. Finally, on page 11, The Access to Credible Genetics Resources Network (ATCG) introduces us to two versions of the Trust It or Trash It? tool: One facilitates evaluation of health information and the other assists in the development of quality educational materials—illustrating again the art and science of communicating information about genetics and health.

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National Dialogue on Genetics in Primary Care Paves Way for Work of RCs

Submitted by Greg Feero, MD, PhD, Special Advisor to the Director, National Human Genome Research Institute, National Institutes of Health and Faculty, Maine-Dartmouth Family Medicine Residency Program

Genomic medicine's full potential to improve healthcare in the United States will take considerable continued investment in biomedical research and changes in how we educate health professionals. For example, genetics and genomics are often taught during the basic science portion of medical school training with little follow-through during clinical training. It is therefore unsurprising that patients affected by genetic disease rate their primary caregivers' knowledge of genetics and genomics as poor.¹ The advent of inexpensive and rapid methods for genotyping and sequencing is fueling a new surge of genomic discovery relevant to patient care. If left unaddressed, the gap between emerging science and clinical application of genomics will widen at an increasing pace over the next several decades.

Though often poorly equipped to do so, primary care physicians are well positioned to recognize and help manage individuals with, or at risk for developing, inherited conditions. Public and private educational activities such as the Genetics in Primary Care Initiative (http://genes-r-us.uthscsa.edu/resources/genetics/primary_care.htm) and the American Academy of Family Physician's 2005 Annual Clinical Focus on Genetics (<http://www.aafp.org/afp/2005/0801/p359.html>) have sought to provide primary care providers with the tools necessary to effectively deal with genetic and genomic aspects of patient care. To date, none of these activities has taken a system-wide approach to integrating genomics across the continuum of primary care education from medical school, to residency, through professional

certification and continuing medical education.

In June of 2009, the National Human Genome Research Institute and partners from the NIH and other Federal agencies including Health Resources and Services Administration (HRSA) and Centers for Disease Control (CDC) hosted a meeting entitled *Developing a Blueprint for Primary Care Physician Education in Genomic Medicine*. Attendees from organizations representing the different stages and types of primary care education convened for a day and a half to brainstorm about the future of primary care physician education, and a subset of members stayed for an additional half day to discuss issues unique to the intersection of genomics and education for providers of maternal and child healthcare. In recognition of the multitude of pressures facing primary care, the goal of the meeting was not to project the priorities of the genetics community on attendees, but rather to generate a dialogue leading to a better understanding of: 1) the educational needs of invitees' constituencies; 2) their priorities for genetics and genomics education over the next five years; and 3) how these needs might be addressed given the competing priorities facing primary care.

The discussions at the meeting were vigorous. There was general agreement regarding the increasing relevance of genetics and genomics to primary care. Attendees recognized the overlapping educational needs of the primary care specialties and the need for educational changes on a systemic rather than *ad hoc* basis. Additionally, the increasing need for partnerships with medical geneticists

and genetic counselors as subject content experts at multiple levels was recognized. More specifically, all agreed that an excellent organizing subject for education would be family history, as each discipline views this as foundational to integrating genomics into day-to-day care delivery. Details can be found in an early draft of the report from the meeting located at www.aacom.org/InfoFor/educators/Documents/Genome-Genetic-blueprint.pdf.

Agreement on the relative priority to ascribe to genomics given the breadth of challenges facing primary care was not easily reached. In particular, attendees raised the need for the development of evidence demonstrating improved health outcomes arising from the use of genomic applications. Several expressed the sentiment that healthcare provider educational time is finite, and that inclusion of additional genomics content will necessarily come at the expense of other topics. These individuals suggested that increasing genomic educational content prior to the development of evidence of benefit amounts to putting the cart before the horse. Other attendees argued that in such a fast moving field, waiting on the development of evidence of benefit, which can be very costly, ethically challenging, and take decades, does both healthcare providers and their patients a disservice. At a practical level, all attendees recognized that in the current fiscal climate funds for major educational initiatives are rate limiting. Clearly solutions to these issues will require additional dialogue and attendees agreed that ongoing meetings of the group would be of value.

"...all agreed that an excellent organizing subject for education would be family history, as each discipline views this as foundational to integrating genomics into day-to-day care delivery."



The content of this meeting dovetails well with the current activities of the Secretary's Advisory Committee on Genetics Health and Society (oba.od.nih.gov/SACGHS/sacghs_focus_education.html), which has had a longstanding interest in improving genetics and genomics education for health professionals. Additionally, newly arising activities such as the Genomic Applications in Practice and Prevention Network (GAPPnet, <http://www.cdc.gov/genomics/translation/GAPPNet/index.htm/>) are

to highlight the need for improvements in genomics content of health professional education. Continuing and expanded dialogue between groups like the Adult Genetics Special Interest Group of the American College of Medical Genetics and those responsible for the education of future generations of primary care professionals will be key to realizing the future of genomic medicine.

The views of the author are his own and are not necessarily those of the NHGRI, NIH or the US Department of Health and Human Services.

¹Harvey EK, Fogel CE, Peyrot M, Christensen KD, Terry SF, McInerney JD (2007). Providers' knowledge of genetics: A survey of 5915 individuals and families with genetic conditions. Genet Med 9(5):259-67.

the new england **negc** genetics collaborative

Submitted by Amy Schwartz, MPH, Project Manager, NEGC and Robert J. McGrath, PhD

Multidisciplinary Study Shows Medical Home Critical to Receiving Genetic Services

Recently, NEGC staff and collaborators from the University of New Hampshire published an article¹ on research that examined the need for genetic counseling services (GCS) for children with autism spectrum disorder, Down syndrome, and intellectual disabilities. The authors also looked at the factors influencing the receipt of needed GCS for those children relative to other children with special healthcare needs. Analysis was conducted on the 2005-06 National Survey of Children with Special Health Care Needs (NSCSHCN), a nationally representative sample.

The analysis found that 14 percent of families of children with diagnoses of autism spectrum disorder, Down syndrome, and mental retardation perceived a need for GCS, compared to 4.3 percent of those families whose children had other types of special healthcare needs (CSHCN) ($p < .001$).

Access to a medical home was found to be the single most important factor in facilitating access to genetic counseling services.

Access to a medical home was found to be the single most important factor in facilitating access to GCS. Children with access to a medical home were on average 2.8 times more likely to have received all needed GCS than those without one (95% CI 1.5 - 5.2). In addition, children whose conditions were rated severe were 1.8 times less likely to get all needed GCS (95% CI 1.0 - 3.1) than those rated as minor. Income and insurance were also significant factors in receiving GCS. Those children coming from poorer households were 1.8 times less likely to receive needed GCS (95% CI 1.0 - 3.1), and those who were uninsured were 50 percent less likely to receive needed GCS (95% CI .2 - .9) than other CSHCN.

These findings support the need for strategies to improve linkages between specialty providers and the medical home. Increased effort should be made to attend to those who experience barriers to access such as lack of insurance, racial or ethnic differences, poverty, and low educational attainment. Collaboration across the health and social policy spectrum is needed in order to develop ways of minimizing disparities in access to genetic counseling services for children with special healthcare needs.

<http://www.negenetics.org/>

¹McGrath RJ, Laflamme DJ, Schwartz AP, Stransky M, Moeschler JB (2009). Access to Genetic Counseling for Children with Autism, Down Syndrome, and Intellectual Disabilities. *Pediatrics*, 124(s4):443-9.

Submitted by Katharine B. Harris, MBA, Project Director, NYMAC

NYMAC Uses Consensus Process to Identify New Projects

HRSA's charge to each of the Regional Collaboratives is to "enhance, improve or expand the ability of state and local public health agencies to provide quality care for screening, counseling and healthcare services to newborns and children having or at risk for heritable disorders." This is no small order in a region that consists of seven states (DE, MD, NJ, NY, PA, VA, WV) and the District of Columbia, and has a disabled population of about 11,490,376 people (estimated from the 2000 and 2009 US census). Fortunately, the NYMAC region includes thousands of dedicated primary care providers, medical specialists, public health professionals, and consumer support and advocacy groups. Many of these people work with NYMAC on projects that will positively affect the lives and health of people (including newborns and children) with disabilities.

On October 28 and 29, 2009, fifty of the most active members of NYMAC convened in Baltimore for a strategic planning meeting. Before the meeting, NYMAC conducted a stakeholder survey of needs and perceptions and a review of current projects and accomplishments. A planning committee, comprised of NYMAC staff, Advisory Council members, and other individuals essential to the RC, designed the meeting to assist NYMAC in developing new projects and achieving our objectives. After a two-hour round-



robin session soliciting each attendee's needs and using trained facilitators, six breakout groups discussed potential projects related to newborn screening, access to care and support services, transition through the life cycle, consumer needs, education, and advocacy and policy.

Over the following few months, NYMAC staff identified a champion and staff member for each of 29 proposed projects and worked with them to define timelines, budgets, products, and outcomes for these projects. Descriptions of the 29 proposed projects were distributed to the NYMAC Advisory Council and discussed during conference calls on January 28 and 29, 2010. Advisory Council members rated each project using a set of criteria that in-

cluded the project's relationship to NYMAC objectives, its potential to meet a critical need, the life stage addressed, the project's feasibility, and its potential for replication. The Executive Staff considered these ratings and the availability of funds and staff time in determining those projects that can be implemented immediately with existing funds, those that should be pursued subject to the availability of additional funds, and those that will not be pursued in this cycle. The NYMAC community looks forward to the implementation of these projects and foresees outcomes that will benefit people's health and lives. We will provide updates on specific projects in upcoming *NCC Collaborator* issues.

<http://www.wadsworth.org/newborn/nymac>



SOUTHEAST NBS & GENETICS COLLABORATIVE

Submitted by Alex Kemper, MD, MS, MPH, Medical Home Workgroup Chair, with Elizabeth Otwell, MSPH, Project Coordinator, SERC

Preparing Primary Care Pediatricians for Genomic Medicine

As part of our regional medical home activities, the Southeast Newborn Screening and Genetics Collaborative (SERC) is offering a special Grand Rounds lecture in genetics and genomic medicine. This one-hour presentation was designed for busy practitioners who may not always have access to medical centers with genetic specialists.

Alex Kemper, a general pediatrician and Chair of our Medical Home Workgroup, developed the lecture based on feedback he received from colleagues on the role of genetics in current care delivery. The talk builds on a recently approved statement from the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children that outlines a strategy for preparing primary care providers for genomic medicine. This statement, of which Dr. Kemper is the primary author, was published in the February 2010 issue of *Genetics in Medicine* and is available here.

Dr. Kemper's lecture was first presented in December 2009 at the Columbus Regional Healthcare System in Columbus, Georgia; a second one is scheduled at the Meharry Medical College in Nashville, Tennessee in April 2010. SERC plans to offer the lecture at least once in each of the eight states in our region.



The presentation is also designed to increase awareness of resources available through the HRSA Genetic Collaboratives among primary

care providers. Therefore, please contact SERC if you are interested in having Dr. Kemper present to primary care professionals in your region or if you have any questions about the presentation. He is available to travel and present in states outside our region or to provide the slide set for others who might be interested in using it to educate primary care providers.

<http://www.Southeastgenetics.org>

The lecture covers:

- the history of genetics, all of the way back to the publication in 1859 of *Origin of Species*;
- an overview of new and exciting areas in genomic medicine, including the role of genetics in common diseases and pharmacogenetics;
- newborn screening and the role of the general pediatrician;
- how to identify genetic conditions in primary care and where to refer;
- family health history;
- genetics and race;
- genetic testing services; and
- resources for learning more about genetics and genomic medicine.

A video of the presentation will be posted to the SERC website in spring 2010. However, we believe that this educational tool has its greatest impact on primary care providers when used as an in-person presentation, since face-to-face discussion is such a critical component of the learning process.



Region 4 Genetics Collaborative

Submitted by Jodi Griffin, MPA, Project Coordinator, Region 4

Sharing Ideas Across Region 4

Promoting the exchange of ideas between our seven states has been fundamental to the many accomplishments of the Region 4 Genetics Collaborative. Region 4 stakeholders understand that ensuring the delivery of high quality services to children with genetic conditions and their families requires a broad group of experts who actively communicate and share new ideas, technologies, and practices. This sharing of ideas has been so essential to the success of the collaborative as a whole that Region 4 has implemented a process to encourage and support a similar exchange at the state level.

During the last year, Stakeholder Meetings were convened in each of the Region 4 states. The purpose of these meetings was to create a shared understanding of Region 4 project goals and new directions for the collaborative, while increasing opportunities for stakeholder partnerships and collaborations at the state and regional levels. Leaders from each state, including family partners, provided input into the agenda for their state's meeting. At the meetings, families, genetics professionals, and other healthcare providers came together to exchange updates on individual state, regional and national activities. Participants brought new opportunities for collaboration to the table, and new partnerships were forged in each state.

Outcomes

New directions for the collaborative were identified. Each state agenda included

a facilitated brainstorming session that resulted in ideas for collaborative projects and future directions. Common project areas identified across the states include: emergency preparedness for families with children who have genetic conditions; a congenital hypothyroidism 3-year follow up study; and engaging each state's sickle cell disease stakeholder communities.

New partners came to the table. Of the 209 total participants, 124 were new to Region 4 and many of the individuals new to the collaborative expressed interest in participating in Region 4 activities, such as workgroups, and providing stakeholder review of collaborative products. The diversity of participants has provided state leadership with a pool of new resources to include in state and regional activities.

Parents actively participated. Nearly one-quarter (56) of meeting participants were parents of children who have genetic conditions. The stakeholder meetings provided an opportunity for providers and parents to discuss and examine issues from multiple perspectives.

These meetings allowed stakeholders to observe how their projects and interests fit into the broader mission and scope of Region 4. The support and partnerships provided by the larger group of stakeholders these meetings engaged will help the Collaborative accomplish the shared goals of providing quality services to children with heritable conditions, and their families.

Sample materials from the stakeholder meetings can be found at the Region 4 website (<http://region4genetics.org/>)

<http://region4genetics.org>



"Overall, I really enjoyed this meeting. I am new to the Region 4 Genetics Collaborative, and this meeting provided a great forum for learning more about what my state is doing and how I could contribute."



Heartland Genetics and Newborn Screening Collaborative

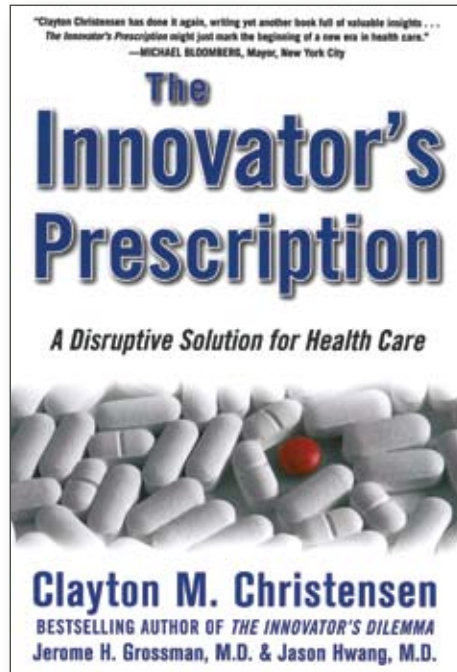
Submitted by John J. Mulvihill, MD, Program Director, Heartland

The “Disruptive Innovation” of Genetics in Healthcare Reform

Adapted from remarks given at the NCC/RC National Meeting, Bethesda, MD, November 17, 2009

HRSA’s Genetics Collaboratives (RC) system is arguably one of the most successful interfaces of the impoverished public health system and the affluent healthcare system, perhaps because the basic science of genetics is its glue. Lessons from the Heartland and other RCs might well inform discussions to address our healthcare crisis. I say this after reading, at the suggestion of ACMG President Bruce Korf, *The Innovator’s Prescription: A Disruptive Solution for Health Care*,¹ and presenting my thoughts at the November 2009 NCC/RC meeting.

The authors use many neologisms, starting with “disruptive innovation,” which refers to abrupt changes in how tasks are done. Familiar examples are in computational tools (abacus, IBM-DEC main frame machine, hand-held calculator, laptop, and massively paralleled processors) and communication tools (smoke signals to cell phones and the internet). In two centuries of healthcare, we have moved from intuitive medicine, to the current *empirical* medicine, to a future of *precision* medicine. This precision innovation is disruptive because it enables, for the first time, exact molecular genetic diagnoses (of microbial, inherited and somatic



gene changes) and uses pharmacogenomics to widen the therapeutic versus toxicity ratio. Unlike a comprehensive academic health center with much surgery and many laboratory methods, genetics is NOT a value-added process (a simple fix-it shop) but rather a “solution shop,” where complex and comprehensive evaluations are often needed to establish diagnoses, there is little reliance on a hospital, and only a short menu of laboratory assays. The third element of disruptive innovation is a valued network, with the common model being a health club (pay a fee to empower fitness and wellness) or WebMD (use the internet to link medical information to those who need it when they need it).

Expanding on the concept of a valued network, we in Heartland, and across the nation, must stay ahead of the curve for networking through

our regional meetings, advisory councils, and advocate partnerships. In several Heartland pilot projects, there are elements of the other disruptive innovations. For example, we just awarded funding for a summer camp for patients and families with PKU in Oklahoma and Arkansas that includes pre- and post-camp assessments of phenylalanine levels. Another collaboration, between Kansas and Missouri, aims to improve access to medical genetics resources for the vast enterprise of personal genealogy. Finally, our state-based Genetics Services Assessment and the interstate newborn laboratory exchanges for emergency preparedness strive to improve systems by promoting quality assurance. Let’s keep disrupting with genetic innovations!

Three Genetic Elements of Disruptive Innovation

Technology enabler:
Precision medicine

Business model:
Solution shop

Valued network:
The HRSA Genetics Collaboratives and their National Coordinating Center

<http://www.heartlandcollaborative.org/>

¹CM Christensen, JH Grossman, and J. Hwang, *The Innovator’s Prescription: A Disruptive Solution for Healthcare*, New York: McGraw-Hill, 2009, pp 441.



Submitted by: Laura Pickler, MD, MPH; KaraAnn Donovan, MSPH; Celia Kaye, MD, PhD, Project Director; Joyce Hooker, Project Manager; and Liza Creel, MPH, Project Coordinator, MSGRCC

Improving Medical Homes and Transition Outcomes for Youth Served in IMD Clinics

Although many people think of primary care physicians when they hear the term “medical home,” comprehensive medical homes for children with special healthcare needs must encompass all the professionals and the family members involved in the care of these children. Thus, the medical home concept has far-reaching implications for clinicians of multiple specialties, including geneticists and inherited metabolic disorders (IMD) providers.

The Mountain States Genetics Regional Collaborative Center (MSGRCC) has funded a project, *Improving Medical Homes and Transition Outcomes for Youth Served in IMD Clinics*, to assess medical home principles related to transition services. We have embarked upon this project because we believe that in the context of the medical home model of care, transition is an ultimate outcome of inter-

est. If other medical home principles are being followed, our hypothesis is that transition outcomes will also improve.

To date, we have developed standards detailing medical home principles and face validation has been completed. These standards have been widely adopted in Colorado and were written into legislation (Colorado State Bill 07-130). Proof of adherence to these standards has been rewarded by increasing reimbursement rates for primary care providers of children with Medicaid insurance.

Our current focus is to develop a draft transition protocol that will be tested in the context of an IMD clinic. To develop the protocol, Dr. Laura Pickler—a clinical geneticist and family practice physician with nationally recognized expertise in medical home and transition of care—is applying qualitative methods to assess current clinical practice around transition and identify a best practice model. Data are being collected from provider focus groups and Dr. Pickler is audiotaping and examining her own conversations with patients to look

for common themes. IRB approval is currently in progress for the next step: IMD staff in Colorado will be trained in the use of this transition model and the project team will assess their knowledge and skills before and after the training.

The Transition to Adult Care National Interest Group, a workgroup of regional and national leaders in transition activities, has helped Dr. Pickler shape this project since she became a member in 2006. The group meets monthly via teleconference to discuss issues related to the implementation of the medical home model in specialty practices.

Future project activities will focus on assessing how the protocol developed in this phase of the project impacts clinical and financial outcomes of interest. We also hope to examine the impact of collaboration among providers on patient outcomes and to develop a model for building successful provider collaborations.

<http://www.msgrcc.org/>





Western States Genetic Services Collaborative

Submitted by Matthew Hirschfeld, MD; Lianne Hasegawa, MS, CGC, Project Coordinator, WSGSC; and Thalia Wood, MPH

Developing a CPT-1A DVD for the Alaska Native Population

In 2004, Alaska began expanded newborn screening (NBS) via tandem mass spectrometry. Like most states in the US, Alaska's expanded NBS panel included screening for carnitine palmitoyl transferase type 1A (CPT-1A) deficiency. CPT-1A deficiency is a fatty acid oxidation disorder that does not allow the body to use fats for energy during periods of prolonged fasting. After a prolonged fast, individuals with CPT-1A deficiency have symptoms that include hypoketotic hypoglycemia, lethargy, and seizures. When screening for CPT-1A deficiency began, physicians and public health professionals thought the condition would be relatively rare, since only about 30 cases had been reported in the literature at that point.

The Alaska NBS Program soon realized that their state had a higher than expected incidence of CPT-1A deficiency; since Alaska began screening in 2004, over 300 newborns have been detected with this condition. They are all from the Alaska Native population, and all carry the same missense mutation—a mutation also found in Canadian and Greenland Inuit populations and in certain British Columbia First Nations populations.

The increased incidence of CPT-1A deficiency in Alaska meant that the community needed to be informed about the condition. Brochures were

sent to all families who had a child diagnosed with CPT-1A deficiency, but many families felt the brochure did not adequately explain screening results. Based on this feedback, Alaska decided that it would be more effective to use visual media and storytelling to convey CPT-1A information to families. There is a rich history of storytelling among Alaska Native people, and using health-related DVDs has been found to be a very effective way of communicating health information in this population.

With funding from the Western States Genetic Services Collaborative (WSGSC), Norton Sound Health Corporation, and Southcentral Foundation, a DVD about CPT-1A deficiency was developed. Dr. Matt Hirschfeld, a pediatrician from the Alaska Native Medical Center, and Thalia Wood, the Children's Health Unit Manager for the State of Alaska, were the executive producers of the DVD and oversaw all aspects of production. The CPT-1 DVD was filmed mostly in small Alaskan villages, since most diagnosed children are from these areas. The DVD uses an Alaska Native narrator, and educational content is presented in story format.

Although the main goal of creating the DVD was to educate the community about CPT-1A deficiency, the secondary goal was to reduce parental stress when receiving this diagnosis. The DVD reviews signs and symptoms of CPT-1A deficiency, but it also emphasizes that most children with this condition are healthy and will grow and develop normally. Many of the children portrayed in the DVD



are playing and running with their friends or eating healthy foods to reinforce the concept that children with CPT-1A deficiency only have health concerns when they undergo a prolonged fast.

Providers and families have evaluated the DVD, and feedback has been very positive. Formal analysis of the results is ongoing, but an initial review revealed that the DVD has been very effective in educating health aides and other providers about CPT-1A deficiency. In addition, families who received the DVD could accurately describe the most important points. This suggests that children in these families, due to increased family knowledge about CPT-1, may receive better healthcare than those who have not viewed the DVD.

WSGGC is thrilled to have contributed to the creation of this important educational project! For more information about the CPT-1 DVD, contact the Alaska Newborn Screening Program at 907-269-3499.

<http://www.westernstatesgenetics.org>

Trust It or Trash It? A Tool for Evaluating and Creating Genetics Health Information

Submitted by Amelia Chappelle, MA, MS, Associate Director of Genetics Resources and Services, Genetic Alliance

Although evidence-based medicine is the gold standard when it comes to clinical care, there is a significant gap in standards for evaluating the quality and content of genetic health information. The Access to Credible Genetics Resources Network (ATCG) developed two versions of the *Trust It or Trash It?* tool: one to facilitate evaluation of health information (www.trustortrash.org) and the other to assist in the development of quality educational materials (www.trustortrash.org/developer). The goals of this effort are twofold: to encourage critical thinking as people encounter health information and to add to the volume of high quality genetics educational materials.

The *Trust It or Trash It?* tool for evaluating information guides users through three questions: Who said it? When did they say it? How did they know? Each section provides examples to help readers think about whether or not to trust the information they are reading. The version used to develop materials provides more details; it also has three scales that cover content, quality, and usability.



Condition-specific advocates, health-care providers, genetics professionals, and health educators all contributed to its development and pilot testing, making it a highly collaborative and iterative process. The next steps for the tool are to program a “widget” that can be hosted on any website, translate it to Spanish, evaluate its effectiveness to help individuals assess information, and disseminate it widely. The “widget” is an application that will open the tool as a static horizontal bar that stays open on the bottom of the computer screen. This application will remind the user of

the elements of the tool to facilitate its use at the time the information is being read. Together these next steps will improve the reach and effectiveness of the *Trust It or Trash It?* tool.

This project is supported by cooperative agreement 5U10DD525036-05 with the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC). If you are interested in embedding the widget on your website, or have questions or comments, please contact Amelia Chappelle at achappelle@geneticalliance.org. For more information on this project, visit www.geneticalliance.org/atcg.

Sample topic areas covered by the developer version of the *Trust It or Trash It?* tool

(www.trustortrash.org/developer)

Content Scale

- Basic Information
What is this condition? What are its features?
- Medical Care
What is involved in getting a diagnosis?
- Developmental Issues
How can I best help my child learn?
- Family Issues
What will this condition cost us, financially?

Quality Scale

- Source of the information
Who is responsible for the content?
- Depth/nature of expertise
What is the basis for the author's expertise?
- Consistency among materials
Is new information substantiated?
- Basis for information
Does the information apply to my situation?
- Type of sponsoring or funding group
Is there potential bias due to funding?
- Date
Is the information up-to-date?

Usability Scale

- Know your audience
- Consider the reading level
- Write your material
- Present your material

NATIONAL CONFERENCES

APHL NBS Meeting	May 3-7	Orlando, FL
IOM Roundtable: Ethical, Legal, Social and Policy Issues Related to Access to, Use and Storage of Newborn Screening Samples Workshop	May 24	Washington, DC
Mid-Year Face-to-Face PD Meeting	June 7	Chicago, IL
Summer Institute in Public Health Genomics: Translating Genomics into Policy and Practice	June 14-18	Seattle, WA
Genetic Alliance Annual Conference	July 16-18	Bethesda, MD
NCHPEG Annual Meeting: Genetics and Public Health	September 23-24	Bethesda, MD

ADVISORY COMMITTEE MEETINGS

SACHDNC Meeting	May 13-14 September 16-17	Washington, DC Washington, DC
SACGHS Meeting	June 15-16	Washington, DC



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Editor-in-Chief Judith Benkendorf, MS, CGC

Associate Editors Alisha Keehn, MPA and Gloria Weissman, BA

Design & Production Lori J. Oxendine, BFA AIGA

Contact Information:

NCC | c/o American College of Medical Genetics | 7220 Wisconsin Avenue, Suite 300 | Bethesda, MD 20814

Tel: 301-718-9603 | Fax: 301-718-9604

ncc@nccrcg.org | www.nccrcg.org

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