NCC COLLABORATOR

Working Together to Enhance Genetic Service Delivery

July 2014 Edition, Volume 8, Number 3

# Improving Access, Coverage, and Care through the Affordable Care Act

Improving access to care for individuals with genetic conditions is a centerpiece of the work of both the seven Regional Collaboratives (RCs) and the National Coordinating Center (NCC). This work is carried on in concert with state and local public health agencies and other partners. In this edition of the *Collaborator*, the RCs and some of their partners highlight activities they are undertaking to maximize the potential impact of the Affordable Care Act (ACA) on access to care. As you will learn, each RC has taken a slightly different approach. Some are working on specific aspects of coverage, e.g., medical foods, some are targeting policymakers, and others are engaging in broader education efforts around ACA writ large.

The New England Genetics Collaborative (NEGC), working through its Healthcare Access and Financing Workgroup, has developed a policy brief that incorporates data from a regional survey on familys' perceptions of gaps in essential services. The policy brief includes information on current out-of-pocket costs and the impact of coverage issues on health and well-being, along with family anecdotes related to these issues.

The New York Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC) is pursuing a number of activities to help its stakeholders understand how the ACA affects them. Of particular note, NYMAC will host workshops in each of its states to examine issues of providing and paying for genetic services and is also working on addressing needs around integrated care systems related to genetics.

The Southeast Regional NBS & Genetics Collaborative (SERC) has been focusing, through the work of its Consumer Alliance, on improving coverage under the ACA for medical foods for individuals with metabolic genetic disorders. The Consumer Alliance has focused on developing legislation in partner states that would require insurers to cover these foods.

Region 4 Midwest (Region 4) utilized its annual in-person meeting as an opportunity for states to learn about and share their payment and reimbursement strategies for improving access to genetic services. Since some insurance options available in these states do not cover the 10 categories of essential health benefits, the RC felt that it was critical for its stakeholders to understand what is covered and what costs families will experience.

The Heartland Genetics and Newborn Screening Collaborative (Heartland) has prioritized educating its states about genetics services and increasing ACA knowledge among providers. The Collaborative is also learning from its stakeholders what their concerns are about the ACA's impact on coverage and access to care.

The Mountain States Genetics Regional Collaborative (MSGRC) has taken a unique approach to promoting ACA implementation by utilizing Facebook and other social media. The region developed model care plans for PKU and sickle cell disease through the supplement awarded to the NCC and RCs. These model care plans will be used in an analysis of coverage across the country.

The Western States Genetic Services Collaborative (WSGSC) is engaged in continually updating the family-friendly, interactive website it developed to help its stakeholders learn about the ACA and find appropriate coverage for their needs.

The National Genetics Education and Consumer Network (NEGCN) is building on its successful outreach and education programs to improve access to genetic services and support. Current efforts are particularly focused on reaching consumers with limited access to technology and on supporting the expansion/"scaling up" of successful model programs.

Finally, in this issue, a parent shares the ways in which advocating for other children helped her after the death of her own child from critical congenital heart disease.

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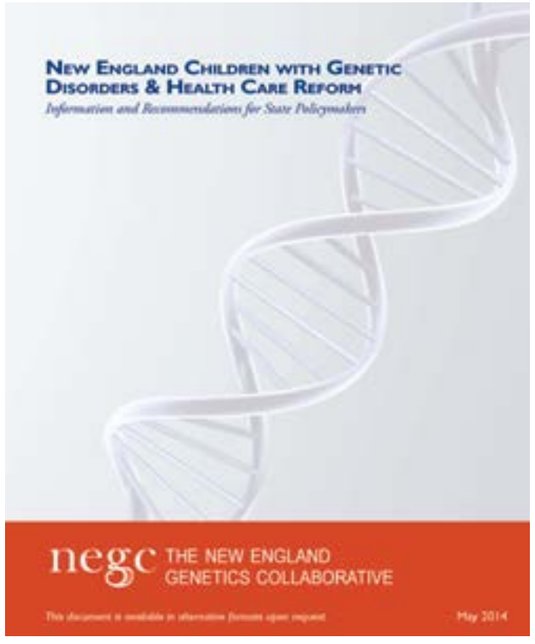
NCC National Coordinating Center for the Regional Genetic Service Collaboratives

# THE NEW ENGLAND GENETICS COLLABORATIVE

## NEGC's Health Care Access and Financing Work Group Studies Coverage Gaps for Families Affected by Genetic Conditions

Submitted by
Adelaide Murray, Public Health Student;
Monica McClain, PhD, Principal Investigator and Co-Director, NEGC

The New England Genetics Collaborative (NEGC) established an informal Advocacy Group during its 2010 to 2011 project year to discuss ways of incorporating advocate feedback into our work. In January 2012, the NEGC's Stakeholder Survey Report identified "addressing financial barriers to care" as a high priority issue. In response, the NEGC created the Health Care Access and Financing (HAF) Workgroup, which is made up of family-advocate leaders and is chaired by Meg Comeau, MHA, of the Catalyst Center at Boston University School of Public Health.




In December 2012, the workgroup began to gather information in order to better understand, from the perspective of families of children with genetic conditions, the gaps in coverage of essential services. The HAF Workgroup designed and disseminated a survey through Family Voices/Parent Information Centers and condition-specific organizations within the New England region. The services referred to the Essential Health Benefits (EHBs) outlined in the Affordable Care Act (ACA).

In December 2013, the HAF Workgroup developed a regional policy brief presenting data from this survey and quotes from families, including information on current out-of-pocket costs, the impact of coverage issues on health and well-being, access issues, and the administrative burden of negotiating with insurance and/or Medicaid systems. The following is an excerpt from the policy brief's executive summary:

"Children with genetic disorders experience gaps in insurance coverage and benefits that put their health and well-being in jeopardy and their families at risk for overwhelming medical debt. Readers are encouraged to learn about some of the strengths and limitations of current health insurance policy as it relates to children with genetic disorders, as well as the multiple opportunities available to improve coverage and care for children with genetic disorders while reducing long term physical, social, and financial costs."

A list of resources is included for each of the following categories: families; health care reform; and data. The policy brief is currently available online and will be disseminated throughout New England to legislators, insurers, professional associations, families, and other stakeholders. Other documents will be produced and disseminated to highlight the challenges and opportunities that are specific to each of the six New England states. Finally, the policy brief will be shared with the other Regional Collaboratives, so that they may create similar documents for their regions.





# NEW YORK-MID-ATLANTIC CONSORTIUM FOR GENETICS AND NEWBORN SCREENING SERVICES

## NYMAC Helping Its Stakeholders Understand How ACA Affects Them

Submitted by
Susanna Ginsburg, MSW, Evaluation Consultant, NYMAC

During the past few years, NYMAC has been engaged in a number of activities to help enhance our stakeholders' understanding of the Affordable Care Act (ACA)' s implications for our target populations. We have also focused on helping providers better integrate genetics into their delivery systems and on helping payers recognize the importance of genetic services and adequately reimburse for them.

A NYMAC ACA Workgroup guides our efforts and is led by Sue Ginsburg, who also co-chairs the NCC ACA Workgroup. Our Advisory Council meetings have included an emphasis on the ACA, even before its passage. In May 2013, the Council heard an important presentation by Meg Comeau of the Catalyst Center and discussed a NYMAC paper, *Implementing the Affordable Care Act in the NYMAC Region*, which identified areas on which NYMAC should be focusing. A companion matrix provided information on the health and insurance status of the population and initial plans for ACA implementation in each state in our region. Using this as a model, the NCC is developing similar matrices for each region, which will be regularly updated.

Other NYMAC activities related to ACA implementation include:

- Workshops in each state to examine the issues of providing and paying for genetic services and overall health care and support for persons with heritable disorders. Attendees include representatives from maternal and child health, other public health-related state programs, Medicaid, private payers, medical providers, and consumer groups. These participants may be meeting together on this issue for the first time. They will share their interests and efforts to date and identify where collaborations are needed to move these efforts forward, with a plan to get started.
- A supplemental ACA grant received by the NCC allows us to address needs around integrated delivery systems. We must help payers better understand genetic and genomic services, consider how to incorporate these in the broader health care delivery system, and determine how to pay for them. A meeting held in March 2014 brought together the NYMAC ACA Workgroup, representatives from the other RCs, collaborators from the National Society of Genetic Counselors, HRSA, and NCC to review the issues and to look at the work already being done by the RCs. The group conversation will be the basis for a discussion paper with background pieces on key genetic and genomic topics. Additional input will be sought from representatives of selected delivery systems and payers. These individuals, as well as those who attended the March meeting, participated in a second meeting in June. The focus of this meeting was be to finalize the NCC project report and to identify how to help individuals/families more fully understand the implications of the ACA for them.

# SOUTHEAST REGIONAL NBS & GENETICS COLLABORATIVE

## SERC Focuses on Improving Coverage for Medical Foods under the Affordable Care Act

Submitted by
Melissa Perez and Kristen Vanags, SERC Consumer Advocates; Lokie Harmond, MPH, SERC Program Manager

Because so many provisions of The Affordable Care Act (ACA) affect children/youth with special healthcare needs, a population important to the Southeast Regional NBS & Genetics Collaborative (SERC), our Consumer Alliance is focusing intently on it and is committed to removing barriers to insurance coverage and to care. The group has developed a survey to track the impact of the ACA on families within the metabolic genetics community. The project's goal is to work with genetic clinics in our region to determine insurance coverage (e.g., for medical foods) and to offer educational resources to families. Data will be collected for three to five years, so that changes in coverage can be evaluated and future needs identified.

Since 2012, the Consumer Alliance has also rallied around the Georgia Medical Food Equity Act. This bill would require coverage for medical foods by all insurance plans regulated by the state of Georgia, in the same way in which these plans cover prescription drugs. The lack of a state mandate for such coverage has created an uphill battle for families trying to provide treatment for their children

with Inborn Errors of Metabolism. In fact, families/adults living with these conditions cannot purchase insurance in the Georgia private market or ACA exchange to cover the medical foods required to prevent disabilities and death.

In 2013, advocates participated in two hearings on the bill. Despite well informed, emotionally compelling, and persuasive testimony from these consumer advocates, the Georgia Advisory Commission on Mandated Health Benefits ultimately voted not to recommend passage of the legislation. The Chair and the Insurance Commissioner cited the general cost of mandates and their negative views on the ACA. Since then, consumers have been collaborating with physicians on the Commission to make refinements to the Georgia Medical Food Equity Act. Although the legislation still faces strong opposition, the Governor of Georgia has recognized the need to maintain medical food coverage for state employees.

Consumers representing various genetic conditions identified through newborn screening continue to work with the Georgia Medical Food Equity Act's lead legislative sponsor to determine the best way of moving forward. Before the Georgia legislative session ended on March 20, 2014, a new version of the bill was reintroduced. Strategies and lessons learned from the Consumer Alliance's work around medical foods are shared regularly with SERC Steering Committee members.

# REGION 4 MIDWEST GENETICS COLLABORATIVE

## Do All Health Insurance Policies Now Cover Essential Health Benefits?

Submitted by
Kathy Neville, JD, MDiv, ACA Consultant/ Contractor, Region 4 Midwest Genetics Collaborative

In April 2014, the Region 4 Midwest Genetics Collaborative brought together stakeholders for a regional meeting. During the meeting, Region 4 provided an opportunity for state teams to learn from each other's' payment and reimbursement strategies to improve access to genetic services for children with genetic conditions. The Affordable Care Act was included in this discussion, and participants were given an update on Essential Health Benefits. Some of the information from that Affordable Care Act session and from the participating stakeholders' questions is included in this article.

Based on media coverage since passage of the Affordable Care Act (ACA), many people believe that current health insurance policies now include all 10 categories of Essential Health Benefits (EHBs). In fact, only some policies do. No matter what a family member's diagnosis is or what service might be needed, families must answer two key questions: "What is covered?" and "How much will this service cost our family?" To obtain relevant information, two different documents are available, but only one will provide the best and most complete answers to both questions.

During the insurance shopping process, consumers will find on all state insurance exchange (and most insurer) websites a "Summary of Benefits and Coverage" (SBC). The SBC is a chart with boxes that contain brief descriptions of each benefit, limitations on the benefit, costs, and some other general information. Examples are included. However, the SBC does not provide all of the detail needed to:

1. Asses medical necessity requirements for service;
2. Complete prior approval requirements that are essential to achieve insurer payment for a service;
3. Appeal in cases in which a denial of payment occurs

A second document, the "Certificate of Coverage," does contain this detail. It is generally only available after enrollment is completed and the effective date of insurance coverage has occurred. In contrast to the SBC, the Certificate of Coverage contains an extensive narrative description for each covered service and identifies when the service will and will not be covered. Definitions of terms, specific exclusions from coverage, prior authorization requirements, and appeal processes are all defined. Often the full document is available online for download at the insurer's website. Mailed hard copies can be requested.

Calling an insurer's customer service number can seem like an appealing alternative. However, reading the Certificate of Coverage section for the service needed before placing a call to Customer Service puts the consumer in the strongest position to assess the answer given. "I have my Certificate of Coverage in front of me and don't see where it says that. Can you tell me where in my policy you found the answer you gave me?" If reference is made to an insurer's internal written document, families should request a copy. Knowing the contents of the Certificate of Coverage provides the best chance of achieving an insurance outcome that benefits each family.

# HEARTLAND GENETICS AND NEWBORN SCREENING COLLABORATIVE

## Heartland to Hold ACA Forum

Submitted by Anayeli Herrera Morales, MPH, Program Coordinator, Heartland; Lori Williamson Dean MS, LCGC, Program Manager, Heartland

In May 2014, the Heartland Genetics Services Collaborative held a two-part Affordable Care Act (ACA) Forum. The goals of the Heartland ACA Forum were to:

1. Provide education to our target population, to key stakeholders that serve this population, as well as to healthcare providers, in order to advance their knowledge about the ACA;
2. Identify common concerns among the states in our region about the ACA as it relates to individuals and families affected by genetic conditions;
3. Learn from stakeholders and decision makers how the Collaborative can address the identified concerns.

Invited stakeholders included Title V directors, Medicaid directors, University Centers for Excellence in Developmental Disabilities (UCEDD) directors, Leadership Education in Neurodevelopmental and Related Disabilities (LEND) directors, Heartland advocates, Early Hearing Detection and Intervention (EHDI) coordinators, state insurance commissioners, state genetics coordinators, state newborn screening coordinators, state genetics clinicians, state Family-2-Family executive directors, and state school nurse consultants.

The first phase of the ACA Forum was an educational webinar presented by Meg Comeau, Co-Principal Investigator for the Catalyst Center, on May 6, 2014. Thirty participants joined the webinar, which was recorded and is now available on the Heartland YouTube channel through the following link: http://youtu.be/dnRiSypEqlA. The goal of this webinar was to provide education on ACA and begin to engage the participants in discussion.

The second phase was a one-day, face-to-face meeting, which took place on May 22nd in Kansas City. The agenda for this meeting included: an ACA update, with focus on the Heartland states, by Captain Jose Belardo from the HHS Region VII office; an overview of ACA-related activities in the Regional Collaboratives by Meredith Weaver of the National Coordinating Center; two strategy implementation presentations for the states of Arkansas and Iowa by David Deere and Angie Doyle Scar, respectively; and breakout sessions during which participants engaged in discussing ACA and providing recommendations on how Heartland may be able to address any identified concerns in their respective states. These recommendations will inform future activities in the Heartland region related to the ACA and our target population.



# MOUNTAIN STATES GENETICS REGIONAL COLLABORATIVE

## MSGRC Develops Care Plans and Uses Facebook to Promote ACA Implementation in the Mountain States

Submitted by Celia Kaye, MD, PhD, Project Director, MSGRC; Kathryn Hassell, MD, Associate Project Director, MSGRC; Joyce Hooker, Director of Regional Outreach, MSGRC

With implementation of the Affordable Care Act (ACA), states have developed Essential Health Benefit (EHB) packages for utilization by insurance providers participating in state insurance exchanges. Although individuals with genetic disorders and their families are participating in these exchanges, the extent to which insurance providers in each state will be covering costs of preventive, diagnostic and treatment services for specific genetic disorders is still unclear. The Mountain States Genetics Regional Collaborative (MSGRC) is working with the National Coordinating Center (NCC) and the New England Genetics Collaborative (NEGC) to define preventive, diagnostic, and treatment services for individuals with three genetic disorders. MSGRC is defining services for PKU and sickle cell disease (SCD), while NEGC is working on fragile X syndrome. The overall goal of the activity is to determine which cost elements of these services are covered within the EHBs and certain insurance plans in the various states and territories of the United States.

MSGRC has supported the development and work of a Metabolic Consortium and a Hemoglobinopathies Interest Group for several years. These groups of providers caring for individuals with inborn errors of metabolism (including PKU) and hemoglobinopathies (including SCD) meet periodically and have successfully completed a number of projects. These include development of a care plan for PKU and plans for dissemination of forthcoming National Heart, Lung, and Blood Institute (NHLBI) guidelines for individuals with SCD, as well as key elements of follow-up for carriers of sickle cell trait. Based on this work, these groups are in a good position to update preventive, diagnostic, and treatment protocols for individuals with these disorders.


The two groups convened for their regular meetings at the MSGRC annual meeting in February, 2014. The Metabolic Consortium reviewed and updated care plans. Still awaiting the NHBLI guidelines, the Hemoglobinopathies Interest Group invited regional sickle cell experts to identify key SCD healthcare services based on available published data and recommendations. Monica McClain from the NEGC joined in these deliberations. In addition, experts on billing for genetic services briefed the groups on preventive, diagnostic, and treatment cost elements included in the EHBs. The working groups compared treatment for PKU and SCD with the EHB cost elements.

The work of the Metabolic Consortium and the Hemoglobinopathies Interest Group has been shared with the ACA Implementation Workgroup of the NCC, as has the work of NEGC on fragile X syndrome. Review by EHB experts and the other Regional Collaboratives will result in templates that can be used in a subsequent project to review state EHBs and insurance plans.

Meanwhile, MSGRC is also enhancing its efforts to use social media, specifically Facebook, to reach a broader audience of families of children and youth with special health care needs. We are focusing on education and awareness about the ways in which ACA may impact them and their children. In March, 2014, MSGRC launched ACA Café, which is a weekly post about ACA definitions, resources, useful websites, and state specific information. The goal of this outreach is to deliver clear, concise, and user-friendly snippets of information "one cup at a time."

# WESTERN STATES GENETIC SERVICES COLLABORATIVE


## WSGSC Maintaining, and Updating Its Unique ACA Website

Submitted by
Jennifer Boomsa, MS, CGC, Project Specialist, WSGSC; Lianne Hasegawa, MS, CGC, Project Coordinator, WSGSC; Jacquie Stock, MPH, Project Evaluator, WSGSC; Sylvia Mann, MS, CGC, Project Director, WSGSC

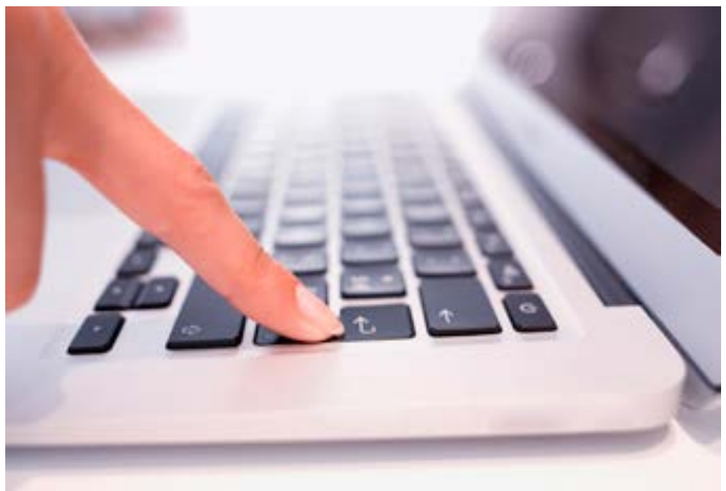
The Affordable Care Act (ACA) is a complex piece of legislation, and, like many people, the Western States Collaborative partners readily admit that they do not understand fully how it affects them or the patients and families they serve. To help provide straightforward information about the ACA, the Western States Genetic Services Collaborative (WSGSC) developed a website that highlights pertinent ACA information and resources in a format that is easy to understand and navigate. The design and unique features of this website were discussed in an article in the February 2014 issue of the NCC Collaborator.

After the initial development of the ACA web resource, three focus groups were held with family advocates, genetic counselors, physicians, and state public health staff, including Title V programs, to review the site's usability, usefulness, format, and content. The website was then revised based on the extensive feedback received from focus group participants. These changes include the addition of two surveys. The first allows website users to provide additional suggestions for improving the site. The second collects personal stories from users about their experiences with the ACA. It is hoped that survey responses can be used to better understand and address the needs of individuals with or at risk for genetic conditions.

The website was made public on October 24, 2013 with a soft launch to limited audiences. Between October 25, 2013 and March 31, 2014, we have had more than 600 unique visitors. Visits to the website peaked in November and decreased during the successive months. The most visited page is the one about the ACA and children with special health needs. All completed feedback surveys have been positive.

It has been challenging to create and maintain an ACA website containing current information and resources appropriate for the general public. New interpretations, rulings, and regulations regarding the ACA and its provisions seem to be announced almost weekly. Having personnel track these changes and then reflect them on the website requires resources. Fortunately, using a team approach, in which all WSGSC staff share the task of identifying new and important information, has helped to reduce this burden.

The ACA has the potential to positively affect millions of Americans, including families with or at risk for genetic disorders. However, these individuals need clear information to help them understand how to best take advantage of these benefits. This is a high priority activity for the WSGSC. We are now planning how to advertise the availability of this ACA web resource more broadly within our region and nationally so that more families and providers can benefit from our efforts.







# NATIONAL GENETICS EDUCATION AND CONSUMER NETWORK

## NGECN Building on Successful Outreach and Education Programs to Improve Access to Genetic Services and Support

Submitted by
Sharon Romelczyk, MPH, Program Manager, NGECN

A common question among the NCC/RC network is how we can have a measurable impact on access to genetic services for individuals and families. How can we create resources and programs that resonate with individuals and inspire them to make changes in their lifestyle or participate in screening or testing? How do we do outreach to populations that aren't accessible through email or the Internet, who may be most in need of our resources and better access to genetic services?

The mission of the National Genetics Education and Consumer Network (NGECN) is to address these very issues. One of NGECN's goals is to learn from successful "model" programs. In December 2013, NGECN worked closely with its Consumer Advisory Group, Parent to Parent USA (P2P), and Family Voices (FV) to create a Request for Proposals (RFP) for "Impact Awards." These awards will support existing outreach/education programs that have evaluation plans in place and allow them to significantly expand their activities and enhance their impact on access to genetic services. Concurrently with the Impact Awards project, NGECN also compiled effective strategies for reaching and engaging populations and produced the *Guide to Successful Outreach and Education Programs*. This guide was made available to the public but also distributed specifically to all the organizations that submitted an initial letter of intent in response to the Impact Awards RFP, so that they would be able to utilize the experience of past projects in writing their proposals.

NGECN received a total of 44 proposals for the Impact Awards, with a range of target populations and project ideas. Proposals focused on a variety of issues, including: education for carriers and carrier screening; awareness and understanding of Jewish genetic diseases; education and screening for hereditary cancer syndromes; parent education around newborn screening; awareness of family health history; and more. In March 2014, reviewers, including several consumer representatives from the Regional Genetics Collaboratives, Family Voices, and Parent to Parent USA, completed an objective review of all of the proposals using standardized evaluation criteria.

The final selected proposals were announced on May 30,2014. Awardees included:

- Boston University School of Public Health
- Gallaudet University
- Nemours A.I. duPont Hospital for Children
- Michigan Public Health Institute
- The Center for Jewish Genetics
- The Hali Project
- The University of Wisconsin-Madison

Beyond the anticipated outcomes from the awarded programs, the process of reviewing proposals helped NGECN further identify the needs of consumers. Each of the proposals identified a population in need of improved access to genetic services. Several of the reviewers pointed out that consumer-focused outreach and education programs can be an effective way to improve systems and services. One area of great need that reviewers discussed was services and support for individuals/families living with undiagnosed conditions.

The Impact Award process also helped NGECN raise awareness of the NCC/RC network. Applicants were encouraged in the RFP to work with at least one RC program, as well as with other community-based organizations.

We anticipate the Impact Awards will encourage organizations to cross silos, develop novel partnerships, and engage with stakeholders around the common goal of improving access to genetic services and support. This project will help further the mission and reach of the NGECN.

For more information about the Impact Awards, visit www.geneticalliance.org/ImpactAwards. Please send any specific questions to Sharon Romelczyk, Program Manager, at sromelczyk@geneticalliance.org.

"The role of consumer engagement and advocacy has only grown more critical, for two main reasons. First, consumer engagement allows for information among peers. Sharing the lived experience of challenging health circumstances along with the outcomes with someone who has traveled a similiar path is, in a word, invaluable to newly identified individuals and families. Second, consumer engagement allows for the development of leadership for individuals who will work to insure systems lead to optimal outcomes and will keep the field "on its toes" when they do not."- Mark Smith, NGECN Consumer Advisory Group Member representing the Heartland Regional Genetics Collaborative

# Consumer Corner

## The Corbin Story

Submitted by
Ruth Caruthers

Parenting is hard. Parenting is even harder when your child has passed away. How do you parent when your child is gone?

After my three-month-old son, Corbin, succumbed to his heart defects, I desperately wanted to help prevent such a loss from happening to another parent. I found purpose and hope in advocating for babies with critical congenital heart disease (CCHD). Little did I know that Corbin's legacy would take me all the way to my state legislators as an advocate for expansion of newborn screening to include pulse oximetry.

I am proud to have helped pass a bill in West Virginia that mandates CCHD screening for all newborns. Along with other advocates and using the American Heart Association's "You're the Cure" network, I encouraged thousands of individuals to send emails to their legislators in support of the bill. Updates on the bill's progress and "calls to action" on social media, including Facebook, my blog about Corbin, and Twitter, helped us gather more followers. It took only three months to pass the bill, and we were on our way to saving babies!

In my three years of advocating for babies in honor of Corbin, I have learned so much about newborn screening, pulse oximetry, and how to get important legislation passed. I also learned about the things we should have tried and realized that other states are learning from our success. My advocacy work on behalf of infants with CCHD has been the most gratifying experience of my life.

The way I am a mother to Corbin has changed since he has passed, but has not lost any meaning or importance. I never thought something as devastating as the death of a child could change one's life for the better, but advocating for babies has helped me through my journey of child loss in ways I couldn't have imagined. Working with organizations like Baby's First Test, Save Babies through Screening, and NYMAC has opened doors I never expected and given me opportunities I am blessed to have experienced.

I am thankful for my work with these organizations and I am looking forward to the next steps in my journey of helping families with CCHD. In the future, I hope to see a country in which every newborn is screened to the fullest and our children are given the best chances of surviving any conditions with which they are born. I hope for life.

Read more at:
www.thecorbinstory.com or
www.facebook.com/thecorbinstory

If you are a consumer/advocate would like to submit an article for the next *NCC Collaborator*, contact Alisha Keehn (akeehn@acmg.net).

# NCC ACA Implementation Workgroup

## Building the Case for Inclusion of Genetic Services in Health Coverage and Integrated Care Systems

Submitted by
Alisha Keehn, MPA, Project Manager, NCC; Sue Ginsburg and Meg Comeau, MHA, NCC ACA Implementation Workgroup Co-Chairs

Within six months of its inception in January 2013, NCC's ACA Implementation Workgroup, comprised of RC experts and other national partners and led by Ms. Sue Ginsburg (NYMAC consultant and evaluator) and Ms. Meg Comeau (Catalyst Center at Boston University School of Public Health), developed two Affordable Care Act (ACA) implementation plans. The first included activities the NCC and RCs could undertake without additional funding, and the second mapped out work that the NCC and RCs could pursue with additional funding. The workgroup, like the NCC and RCs, sees its overall mission as improving access to care for individuals with genetic conditions, but is focusing specifically on the ACA's potential impact on stakeholders within the NCC/RC system.

In September 2013, HRSA awarded the NCC, as the fiscal agent for the NCC/RC system, a supplement to support the following three projects suggested by the ACA Implementation Workgroup:

1. Three Model Condition Cost Elements Identification and Analysis
   Two RCs, MSGRC and NEGC, are leading a project to ascertain cost elements across the lifespan for three genetic conditions, phenylketonuria (PKU), sickle cell disease, and fragile X syndrome. The templates are complete and are awaiting final approval by the full workgroup and HRSA.

2. Sample State Analysis of the Three Model Conditions Cost Elements
   Working with NCC's ACA Workgroup, the Catalyst Center (http://www.hdwg.org/catalyst/) has developed a framework for choosing health plans in a representative sample of states to review the three model condition templates against selected health coverage plans (e.g., Medicaid Alternative Benefit Plans; State Health Insurance Marketplace Benchmark Plans ) to determine health benefits for these conditions. This project is underway and is expected to conclude by September 2014.

3. Considerations for a Standardized Genetics Component in Integrated Delivery Systems
   Directed by NYMAC, under Ms. Sue Ginsburg's stewardship, this project seeks to provide considerations for what a genetic component of care looks like and how to make that component an integral part of the care delivery system. The group is examining how to define the value of a genetic component and how inclusion of such a component across the lifespan affects management of care and helps to achieve better outcomes. Working with RC experts, integrated care system representatives, and other national leaders, a small group meeting held in March 2014 explored the types of information needed by integrated delivery systems and payors to make decisions regarding genetic/genomic services. Another, expanded meeting is planned for early fall, with the ultimate goal of producing an outline of what the considerations for a standardized genetics/genomics component in integrated delivery systems/accountable care organizations should be. Additional funds will be required to vet and test the outline.


The ultimate goal of activities undertaken with this supplement is to help build the case for including genetic-related specialty services in public and private health insurance programs. The projects will provide the educational and informational foundation for future activities of the NCC/RC system related to engaging local, state, and national leaders in addressing gaps in coverage and access to genetic services for those utilizing health coverage through ACA.

# NCC CALENDAR

## NCC and RC Meetings

| | | |
|---|---|---|
| Southeast Region NBS & Genetics Collaborative Annual Meeting | July 17-19 | Ponte Vedra, FL |
| Western States Genetic Services Collaborative | Oct 7-8 | Seattle, WA |
| NCC/RC PD/PM Annual Meeting | Nov 6-7 | Washington, DC |

## National Conferences

| | | |
|---|---|---|
| DACHDNC Meeting/Webinar | Sept 11-12 | Washington, DC |
| National Society of Genetic Counselor Annual Education Conference | Sept 17-20 | New Orleans, LA |
| American Academy of Pediatrics Annual Meeting and Exhibition | Oct 11-15 | San Diego, CA |
| APHL Newborn Screening and Genetic Testing Symposium | Oct 27-28 | Anaheim, CA |

## Mark Your Calendar!

NCC/RC Project Director and Project Manager
Annual Meeting
November 6-7, 2014
Washington, DC

RC/LEND
In-Person Meeting
November 8, 2014
Washington, DC

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National Coordinating Center
for the Regional Genetic Service Collaboratives

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