CALL-ON CONGRESS

Advocacy**Handbook**2014

FIGHT COLORECTAL CANCER

Dear Friends and Advocates,

For the last eight years, Fight Colorectal Cancer has made it our mission to empower survivors, family members and loved ones across the country. We recognize that many important decisions about treating colorectal cancer are made in your doctor's office, but there are still more that are made in our government. Elected officials make decisions every day about health issues that impact our lives and the lives of survivors across the country.

Challenged by the 2nd leading cause of cancer deaths for men and women, we too often see patients who have battled the healthcare system and who have lost someone too soon. As a cancer advocacy organization, we know firsthand how important these decisions are to advocates across the country. We understand the value of medical breakthroughs that can lead us to better treatments and prevention of this disease.

Lawmakers have the power to improve access to screening by passing policies and budgets that support medical research efforts. It is our belief that conquering colorectal cancer is as much a matter of public policy as it is scientific discovery. These are efforts that go hand in hand, and we steadfastly support them both.

We hope this handbook will provide you with useful tools that will encourage you to embark on your own journey as an advocate. Ultimately, the power lies in you. Your voice and story will remind our local, state and national leaders, including our members of Congress, that they must rise above partisan politics and focus on saving lives. Colorectal cancer is a national priority.

Sincerely,

Anjee Davis
Interim Executive Director
Fight Colorectal Cancer

ONE MISSION
COMMUNITY
UNITED
WARENESS
SURVIVOR
SUPPORT

Acknowledgements

In creating this handbook, we are deeply indebted to our Fight Colorectal Cancer community members around the country who work to facilitate advocacy and awareness efforts for the sake of colorectal cancer prevention. We are grateful to the advocates and donors who share in the mission of Fight Colorectal Cancer.

It is our hope that the tools outlined in this book will support a movement that empowers those touched by colorectal cancer to raise their voices and push for positive changes in policy that reflect the needs of colorectal cancer patients, survivors and caregivers – and that communities will be transformed in pursuing this mission.

Thank you to everyone who played a role in the writing and design of this handbook.

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Our Mission

Fight Colorectal Cancer demands a cure for colon and rectal cancer. We educate and support patients, push for changes in policy that will increase and improve research and empower survivors and those touched by colorectal cancer to raise their voices against the status quo.

We offer support for patients, family members and caregivers, and we serve as a resource for colorectal cancer advocates, policymakers, medical professionals and healthcare providers. Additionally, we do everything we can to increase and improve research—at all stages of development and for all stages of cancer.

WHAT IS ADVOCACY?

Advocacy is pushing for policy change that benefits a cause. At Fight Colorectal Cancer, our advocacy efforts use the voices of those touched by colorectal cancer to change policy. We strive for our advocates to be confident in their ability to share their stories, meet with legislators, and push for improved policy, and we accomplish this by giving them the tools they need on both national and local levels.
We believe in mobilizing advocates and training them to become voices for the colorectal cancer community, both on the Hill and at home.

In March we host our annual event on the Hill, Call-on Congress, where advocates are trained on the ins and outs of advocacy. Survivors and family members come from across the country to gather and meet with key policy makers. But that's not where we stop. As a national advocacy organization, our goal is to build a network of advocates on a local, grassroots level. In 2013, we launched our Town Hall Meetings series. A Town Hall Meeting is an opportunity for us to come to your hometown to train advocates. There is so much you can do from home -- from using social media (eAdvocacy), writing letters and emails to elected officials, meeting with elected officials and staff, and hosting local events. At the end of the day, it's hearing personal stories from survivors, caregivers, family, and friends that will compel legislators to become emotionally attached to an issue. Once that happens, our chances for success are greatly increased.

It is at the heart of our mission to empower survivors and others touched by colorectal cancer to raise their voices against the status quo. We are committed to supporting and promoting patients' health care rights and enhancing health and policy initiatives that focus on the availability, safety and quality of care. Colorectal cancer is a national priority, and we need your help to change policy for the better.

"Through advocacy, I can do something meaningful to fight the disease that almost killed me. It is a way I can tell others that there IS hope, and fighting back is an option. I can point out victories in the past and the importance of looking to the future for new treatments and, of course, a cure someday. I know that it was, in part, the work of advocates that made my treatments successful." —**Elaine Newcomb**, GAC member

OUR GRASSROOTS ACTION COMMITTEE MEMBERS

Grassroots Action Committee (GAC) is the catalyst of our grassroots advocate community. These active advocates serve a two-year term and help us achieve our strategic goals and objectives.

Jennifer Bretsch, **Alexandria, VA**

- » *Connection to Colorectal Cancer: Caregiver for and supporter of her friend Shawn Felty who had colorectal cancer*
- » 4-time Call-on Congress attendee

Rose and Eric Hausmann, **Morgan, NJ**

- » *Connection to Colorectal Cancer: Rose (stage III colon cancer survivor) and Eric (caregiver and supporter for Rose)*
- » 4-time Call-on Congress attendee

Tom Foeller, **Portland, OR**

- » *Connection to Colorectal Cancer: 6 year stage III colorectal survivor*
- » 4-time Call-on Congress attendee

Elaine Newcomb, **Alpine, WY**

- » *Connection to Colorectal Cancer: 3.5 year stage IV colon cancer survivor*
- » 3-time Call-on Congress attendee

Pamela Seijo, **Grandview, WV**

- » *Connection to Colorectal Cancer: Diagnosed August 17, 2000 with aggressive rectal cancer*
- » 7-time Call-on Congress attendee

Doug Sharp, **Prairie Village, KS**

- » *Connection to Colorectal Cancer: Lost a dear friend to colon cancer*
- » 4-time Call-on Congress attendee

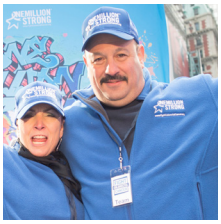
Josh Wimberly, **Mobile, AL**

- » *Connection to Colorectal Cancer: Rectal cancer survivor*
- » 5-time Call-on Congress attendee

What Motivates You to Be an Advocate?

Belle: *"I'm an advocate because if there is one person, one family, that I can save from having to experience the hell of colorectal cancer, all my efforts will have been worthwhile."*

Rose and Eric: *"Knowing that our voices are a part of a collective voice that demands to be heard in the fight against colorectal cancer motivates us to be advocates."*



Josh: *"I am motivated to be an advocate so I can be a voice for colorectal cancer survivors and caregivers."*

Pam: *"Being able to speak and fight for those that are no longer with us, those going through the diagnosis, and those yet to be diagnosed."*

Tom: *"I'm motivated to be an advocate so others don't needlessly go through the agony, expense and other negative impacts of this disease when it can usually be treated or cured if caught early!"*

Jennifer: *"I'm motivated to be an advocate so I can represent CRC patients past, present and future. There is so much need to improve research, prevention, education, treatments, and survivorship care."*

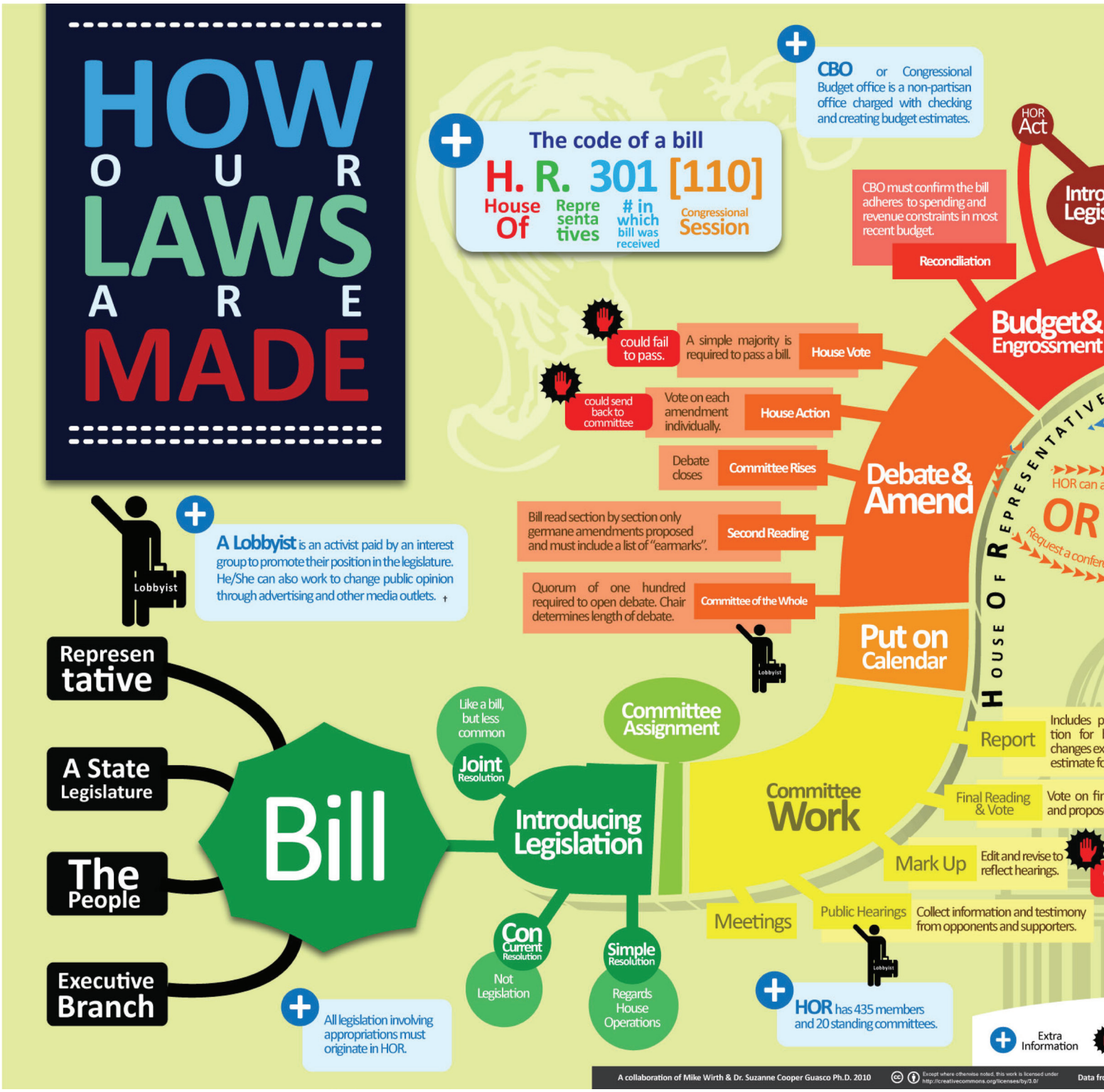
Elaine: *"We must make Congress aware that adequate funding of colorectal cancer research is vital in the fight to find a cure for this #2 killer cancer."*

Michell: *"My family's story doesn't have to be you family's story. Be your own advocate and get screened!"*

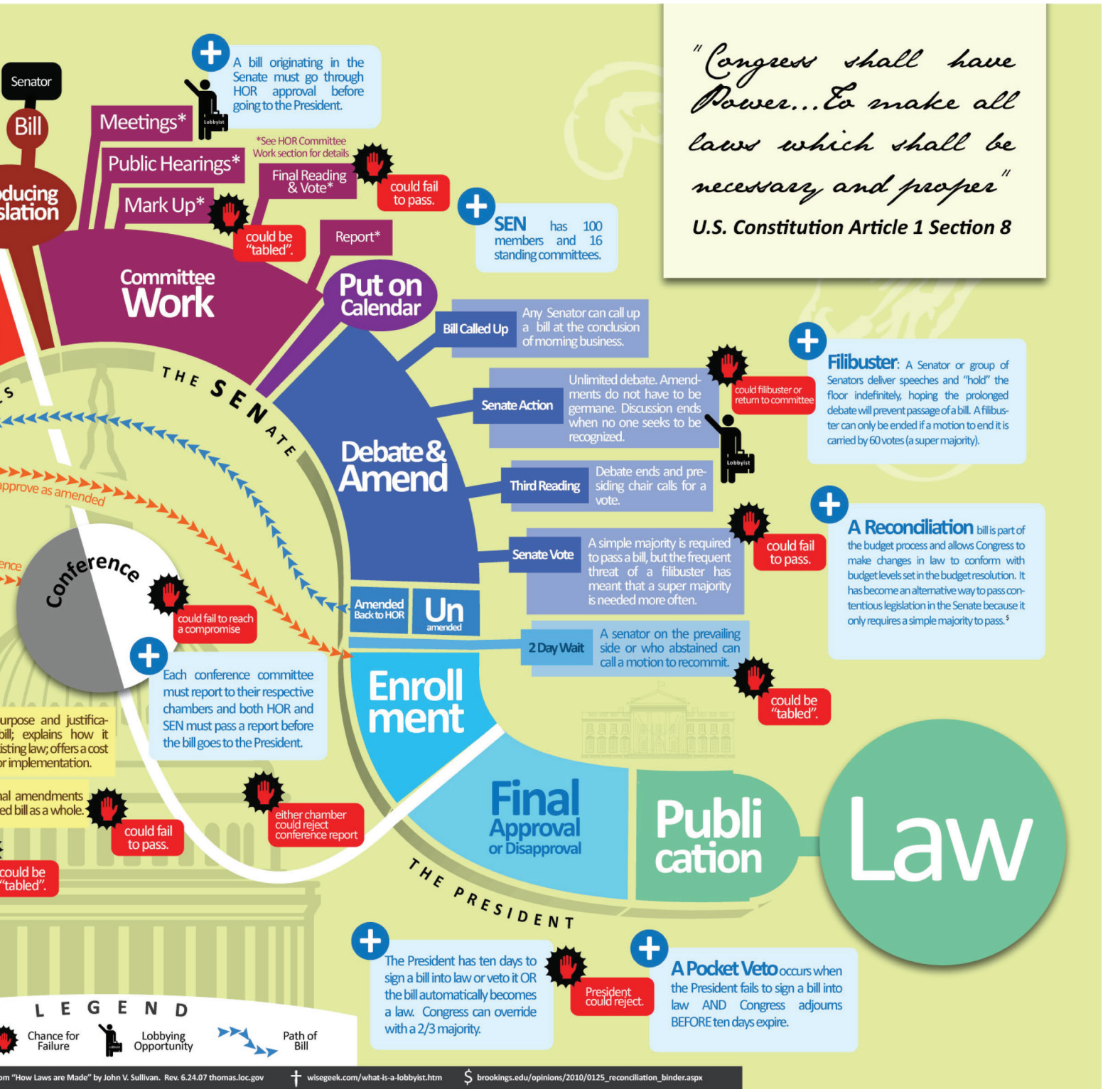
Patti: *"It is the spirit and memory of my husband that initially motivated me to advocate for awareness of CRC, but now I carry the strength of every other survivor I've met along the way!"*

UNDERSTANDING THE LEGISLATIVE PROCESS

The primary work of our Congress is to make laws. Thousands of bills are introduced during each session of Congress, but few are ever enacted into law. The deliberative process that determines which proposals become laws is long, complex and often tortuous. This award winning infographic, created by Mike Wirth and Dr. Suzanne



Cooper-Guasco, professors at Queens University of Charlotte, explains the complex process of how a bill becomes a law. Seeing the steps laid out helps us better understand how to get involved and work with our elected officials to meet needs and solve problems affecting colorectal cancer research funding, treatment services and access screening.



WHY TRACK A BILL?

Tracking a bill helps you hold policy makers accountable. When important pieces of legislation are introduced, the next step as an advocate is to monitor the process as a bill goes through the key steps to becoming a law.

When tracking a bill, you should look for any changes to the bill, where it is in the legislative process, and what its potential impact will be. Make sure you join our Advocacy group on Facebook where we post monthly advocacy updates. This Facebook group will keep you informed on what's happening, and specifically, what we're doing on the Hill, as well as help you connect with other advocates.

HOW TO TRACK A BILL

1. Go to govtrack.us and click on START TRACKING under the TRACK tab.
2. Start with a search or use a pre-set tracker to begin following legislative activities: Start with a search or use a Pre-set Tracker to begin following legislative activities.
   - » For example, type in H.R. 4120 in the search field
   - » Once you click on the H.R 4120 bill, choose to track the bill or take a position.
3. Follow your bills and activities that you've chosen to follow by viewing YOUR DOCKET under the TRACK tab.

UNDERSTANDING THE LEGISLATIVE PROCESS

REVIEW of HOW OUR LAWS ARE MADE

THE FEDERAL LEGISLATIVE PROCESS

While there are some procedural variations, our policy makers pass legislation in the following manner:

- The bill idea is introduced, given a bill number, and assigned to a subject matter committee.
- Committee holds public hearings on the bill.
- Committee debates the bill, makes changes, votes on whether to move the bill along.
- The bill moves to any other committees that need to review it, changes are made if desired, and the bill is voted on if support remains.
- The bill is put into official legal language and placed on the calendar of the House or Senate for debate.
- The bill is debated and amended if necessary, and if passed, is sent to second body of Congress (House or Senate) and scheduled for debate.
- If second body agrees with changes made and approves the bill, it is sent to the President for approval. If body disagrees with changes or makes new changes, the differences must be agreed upon by both houses before the bill can have final approval.
- In many cases, a conference committee including members from each house works on a compromise that is then either approved or disapproved by both houses.

The President has 10 days to sign the bill into law, veto it, or let it become law without his signature (pocket veto). If vetoed, the bill can still become law if two-thirds of both legislative bodies vote to override the veto and approve it.

ADVOCACY ON THE HILL:
MEETING WITH YOUR CONGRESSIONAL MEMBERS
Annual Call-on Congress

Call-on Congress is our largest advocacy event, held each March. Advocates participate in two days of advocacy training where they are briefed on the issues most important to colorectal cancer and learn how to effectively communicate their advocacy goals to their legislators. On the third day of the event, advocates visit with the offices of their representatives and senators, sharing their stories and speaking up about legislative priorities of concern.

Call-on Congress 2013 was our largest hill day yet, having grown participation by 20%! With over 80 participants, 104 Hill meetings scheduled and 24 states represented, we strive for Call-on Congress to grow in participation and impact each year by showing Congress that colorectal cancer is a national priority!

MAKE YOUR (VIRTUAL) VOICE HEARD!

Social media tools aren't just for sharing funny pictures with your friends! Congressional offices are using social media to help stay connected and listen to public opinion on current issues. We encourage you to utilize social media as an advocacy resource and become an e-Advocate! For more help with e-Advocacy, visit FightColorectalCancer.org/eAdvocacy.

BE A VOICE FOR CHANGE!

Congressional offices are using social media to stay connected to their constituents and listen to public opinion on current issues. We encourage you to utilize social media as an advocacy resource and become an e-advocate!

Social media is all about connecting with others! Connect with advocates across the nation so that you can unite as one loud voice in the fight against colorectal cancer.

This checklist will give you the skills you need to get started. Discover how to use each platform, learn the social lingo and realize the importance of those "#" signs. At the click of a mouse or swipe of a finger, you become an e-advocate for change!

GET STARTED

- ☐ Sign up for social media accounts
- ☐ Your online profile is essential to building social relationships and creating online credibility!
- ☐ Upload a professional picture, use your real name and tell about your connection to colorectal cancer in the "About Me" section.
- ☐ Send friend requests to your friends and family on Facebook and "Follow" them on Twitter, Pinterest, YouTube and Instagram
- ☐ "Like," "Join," and "Follow" Fight Colorectal Cancer.

Did You Know?

Congressional offices are using social media to help gauge public opinion, augmenting traditional tools used for that purpose.*

WEBSITE: www.FightColorectalCancer.org/Advocacy

We are a one-stop shop! Find everything you need to take action from policy updates, monthly Advocacy Updates and legislative priorities.

- ☐ Learn about colorectal cancer
- ☐ Read our legislative priorities
- ☐ Read about becoming an advocate locally or on the Hill
- ☐ Take action by sending emails and signing online petitions

Did You Know?

Congressional offices are using social media to help gauge public opinion, augmenting traditional tools used for that purpose.*

Facebook.com/FightCRC

Use Facebook to build relationships with your elected officials. Start by clicking "Like" on their Facebook Page and join discussions by commenting or posting on their pages.

- ☐ Join the Fight Colorectal Cancer Advocacy Group to connect with other advocates and stay updated on what we're doing on the Hill.
- ☐ "Like" or "Comment" on elected officials' individual posts frequently to get their attention. If they allow it (some don't), post a message on their Wall.
- ☐ If relevant, "Share" your representatives' posts on your wall.
- ☐ Post one of our suggested messages to your representative's walls, found at FightColorectalCancer.org/eAdvocacy.
- ☐ "Share" posts from Fight Colorectal Cancer's Facebook page on your profile to gain attention of our cause!
- ☐ Post one of our suggested status updates, found at FightColorectalCancer.org.
- ☐ Use a Fight Colorectal Cancer header for your profile image! Download an image to be your cover photo at FightColorectalCancer.org/eAdvocacy.

Did You Know?

Nearly three-quarters (74%) of the senior managers and social media managers surveyed think Facebook is somewhat or very important for communicating their Members' views.*

Twitter.com/FightCRC

Twitter is a microblogging social media platform used for sending or posting short snippets of information. Each public post (called a "tweet") is limited to 140 characters, but you can communicate privately with other users by using the Direct Message feature. Since you can search tweets by category using the "#" symbol, Twitter is a great tool for following a special event or conference.

- ☐ Make a quick shout out to your congressmen using 140 characters or less. Tag them using the "@" symbol and their Twitter names (called a "handle"). For example: "Thanks @RepDonaldPayne for supporting colorectal cancer research and screening!"
- ☐ Tag us in your posts! Add "@FightCRC" to any post involving colorectal cancer advocacy—we might even retweet you!
- ☐ Retweet a post from Fight Colorectal Cancer so that all of your followers can see it
- ☐ Use relevant hashtags (#) to help categorize and follow topics; the more times a hashtag is used, the more popular it becomes and the more likely it is to be seen.
- ☐ Post one of our suggested status updates, found at FightColorectalCancer.org/eAdvocacy.
- ☐ Use a Fight Colorectal Cancer header for your profile image! Download an image to be your cover photo at FightColorectalCancer.org/eAdvocacy

Instagram: @FightCRC

Instagram is a picture-sharing social media network you can use to take, upload and edit pictures and videos that are then shared with your followers. Pictures and videos from Instagram can also be shared to Facebook and Twitter.

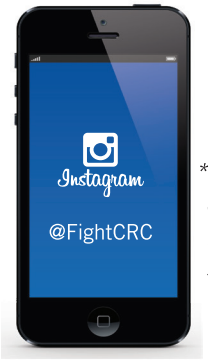
"Follow" @FightCRC and "Like" or "Comment" on our pictures and videos.

Take a picture with your elected officials.

Tag @FightCRC and use some of our suggested hashtags.

Search for your congressmen and follow them if they have accounts.

"Comment" and "Like" your Member's posts, if appropriate.



*Instagram can only be used on smartphones**

Pinterest.com/FightCRC

Pinterest is like an online scrapbook. Each user can create multiple boards, each of a different topic (Blue Trends, Colorectal Cancer Advocacy, Health and Fitness, etc.). Follow your friends, FightCRC, and other survivors. Their pins will show up on your homepage —when you see something you like, click "Pin" and add it to one of your boards. You can browse specific types of pins by selecting a category.

Create a board for Colorectal Cancer Advocacy.

Pin inspirational quotes, empowering images and anything relevant to colorectal cancer policy.

Repin things from the FightCRC boards.

Upload your own pins! All you need is a link to the original source.

Did You Know?

A strong majority of staffers (72%) believe that social media allows their Members to reach people they had previously not communicated with.*Members' views.*

YouTube.com/FightCRC

YouTube is a video sharing social media site. You can watch others' videos or upload one of your own.

- ☐ Search to see if your elected officials have a YouTube channel and subscribe to it if they do
- ☐ "Like" and "Comment" on elected officials' videos, if appropriate
- ☐ Watch Fight Colorectal Cancer's videos (You can also find some of our videos on Vimeo.com/FightCRC)
- ☐ Post a link to Fight Colorectal Cancer's videos on elected officials' Facebook pages or "Tweet" them the link so that they can learn who we are and what we're fighting for!
- ☐ "Share" our videos with your friends on Facebook and Twitter –post a link to your wall!

Scan me with your smartphone to view a video!

LEARN THE LINGO

Each social media site has its own language, and we know it can be confusing! Here are some definitions and tips on using common features.

@ *Reply: Use this to address a public message to a user*

RT *Retweet: This indicates a posting is a retweet from another person*

DM *Direct Message: You can only send a direct message to someone who is following you*

LIKE *This allows other users to know if you appreciate a post*

STATUS *A microblogging feature to inform others of your actions and thoughts*

TAG *Marks a photo or video with text to identify a person*

Activity: *Click this to see recent activity. Select "Following" to see the activity of those you follow or "News" to see activity on your own posts (likes & comments).*

LIKE *YouTube users have the ability to vote a video up or down with "Like" or "Unlike" buttons*

VIEW *Usually refers to viewer count, which keeps a record of the number of views a video receives*

Pin it *Click this button to add the pin to one of your boards*

Website *This button will take you to the original source of the pin. You can also go to the original source by clicking the pin itself. Going to the original source will give you more information about the picture in the pin.*

Like *Shows the user that you like that pin*

Send *The send feature allows you to privately share a pin with a particular user(s)*

Use this feature to share the pin on your Facebook or Twitter accounts or to obtain a link to the pin

#HELPWITHHASHTAGS

Hashtags aren't just for Twitter! You can use hashtags on almost all social media platforms to categorize and group your posts. Search others' hashtags (i.e., #coloncancer) to see what other advocates are up to and encourage them to check out @FightCRC!

Use the hashtags below to make the most of your e-Advocacy efforts:

#1MilStrong
#RectalCancer
#CRCresearch
#FightCRC
#FightCRCAdvocate
#ColonCancer
#ColorectalCancer
#CRCadvocate
#CancerSurvivor
#CRCawareness

*Source: #SocialMedia, Congressional Management Foundation, 2011

ADVOCACY MEETINGS YEAR-ROUND

If you are unable to join Fight Colorectal Cancer at Call-on Congress in March, you can schedule your own appointments with your legislators in Washington, D.C. or at a local office. A great time to schedule a local meeting is during a congressional recess, which is from the beginning of August to mid-September for the House, and from the beginning of August to the end of December for the Senate. Most senators and representatives have a place on their websites for you to request a meeting. If you plan on setting up a congressional meeting, email Advocacy@FightCRC.org for help along the way.

Your Congressional Meeting

It's normal to have butterflies before your Congressional meeting. Take a few deep breaths and remember why you're there. What you're doing is important! Congressmen receive tons of letters and emails each day, so by meeting with them face-to-face and sharing your story, you're putting a face to colorectal cancer. Here are some tips on making an impact before, during, and after your visit with your congressmen.

Before your meeting

Keep your thoughts organized – outline talking points and stick to the key issues. Be punctual – arrive early if you can. This will give you time to collect your thoughts and review your notes.

Be prepared – do your research! Before your meeting, be sure to find out where your legislators (usually) stand on similar health issues. Visit www.FightColorectalCancer.org or email Advocacy@FightCRC.org for downloadable materials, such as legislative priorities and talking points that you can study beforehand and take with you to your meeting. These materials will help you talk through key legislation with your elected official. If you need help finding where your elected official stands, please contact our team at Advocacy@FightCRC.org.

During your meeting

DON'T be political. You want your member of Congress to remember your story, not your political views.

Be responsive. Answer questions from your legislator with honesty and compassion. Make your answer brief, but to the point. If you don't know the answer, don't fret! You have resources to find out the answer after the meeting and you can include it in your follow-up.

Your story is powerful. Emphasize how these issues impact you impact you personally.

Keep it simple – too much detail can muddy your message.

Leave behind information after the meeting for the staff and legislator to refer. If you're meeting outside of our Call-on Congress event, contact us for tools for your meeting and materials for you to leave behind.

To conclude the meeting, ask to take a photo with your elected official.

After your meeting

Fill out a Legislator Post-Visit Worksheet, available at FightColorectalCancer.org.

Send a thank you letter or email to the legislator as well as any staff you may have met with following your meeting. This not only shows the legislator that you appreciate sharing their time, but it also gives you the opportunity to remind them once again about your issue. Use our Post-Visit Thank You Email Template, available at FightColorectalCancer.org.

Post on the legislator's Facebook wall or send them a Tweet to let them know how much you appreciated being able to meet with them.

Send any follow-up information or materials that you mentioned during your visit. Share the story of your visit with others! Post to Facebook, Twitter, Instagram, YouTube, and Pinterest.

"Come here as much as possible. Make sure 435 members of Congress know how important this is. It's the only way you get your message out. Emails are nice. Letters are nice. But face-to-face with members of Congress really gets your message across."

ADVOCACY AT HOME

Fight Colorectal Cancer understands that you're busy! So even if you can't make it to Call-on Congress, you can make a difference. Fight Colorectal Cancer encourages you to be an advocate year-round from home. Whether you want to advocate via social media or host your own Town Hall Meeting, there are many ways and levels of involvement.

Here are just a few things every advocate can do from home:

- Push for a state proclamation
- Write letters and emails to your legislators
- Use the media
- Write a press release
- Write letters to the editor
- Build coalitions
- Meet with legislators
- Host an event
- Town Hall Meeting
- Million Strong March

"Always start with people you know; friends, family, and community members, these are your best resources. Never be discouraged with the word NO, because when one door closes, several will open. Never be afraid to ask for help. The world is full of gracious wonderful people--lean on them!"—**Michell Baker**, GAC Member

"Everyone has a voice and can speak up to friends, family and neighbors about colorectal cancer. Anyone can write a letter to the editor...and anyone, at any time, can write, call or visit their legislators to express their concerns over support for funding, which plays a role in colorectal cancer research, treatment and support. Blogging helps me get the word out to the masses and helps let people know that one voice CAN and WILL make a difference!" —**Belle Piazza**, *survivor & Grassroots Action Committee member*

ADVOCACY AT HOME

PUSH FOR A STATE PROCLAMATION

One of the easiest things to do is securing a state proclamation declaring that March is Colorectal Awareness Month. Fight Colorectal Cancer wants to see all 50 states go BLUE, and it's never too early for you to get started! When states declare March as Colorectal Cancer Awareness Month, it increases awareness and aids in cancer prevention.

For instructions and materials on how to ask YOUR state to go BLUE, visit FightColorectalCancer.org and click on the State Proclamation Toolkit, found under the Change Policy section.

WRITE LETTERS AND EMAILS

If you cannot meet with your member of Congress face-to-face, you can still rely on letters and emails. They're a reliable way to communicate your priorities – and your elected officials need to hear constituent feedback!

Below are tips if you'd like to write to your elected officials.

Proper Forms of Address and Salutations for Elected Officials

"Dear Senator Smith,"

Federal Office: The Honorable John Smith U.S. Senate Russell Senate Office Building Washington D.C.	**Local Office:** The Honorable John Smith U.S. Senate 1015 Main Street Hartford, CT
"Dear Congresswoman Johnson," The Honorable Jane L. Johnson U.S. House of Representatives (Address found on his/her website)	**"Dear Mr(s). Chairman,"** The Honorable James F. Flincher, Chairman House Committee on Healthcare Legislative Office Building Washington, D.C.

Helpful tips for writing a government official:

- Utilize the proper form of address and salutation.
- State Bill Number and title, what it does, and ask for support or opposition. (For tips or a list on colorectal cancer legislation, visit our Advocacy Center at Fight ColorectalCancer.org.)
- Explain why the Bill is needed.
- Indicate any knowledge you have of legislator's past positions, and personalize the message with your story and why it is important to you.
- Conclude by asking again for support of your position.

USE THE MEDIA

Write a Press Release

Having your event covered by news outlets is a big deal and it's not hard to do—all you have to do is submit a press release! Some newsworthy events where a press release is warranted include a public hearing testimony, a fundraising event, or a Town Hall Meeting hosted in your city – especially if an elected official attends!
Use our generic press release template as a formatting guide. You can find it at FightColorectalCancer.org. Put in your event's specific information to make it your own!

As you get ready to make your release, be thinking about:

- A headline and first paragraph that tell the story
- Quotes from key individuals that media can use to emphasize your view
- Description and some details of the issue/event
- Supporting facts

If you need help writing your press release, contact Web@FightColorectalCancer.org!

Letters to the Editor

All newspapers encourage letters, and the editorial page is generally one of the most widely read and talked about sections of the newspaper. You can submit your letter by mail or email and find the contact information in the same section that the letters appear.

Tips for writing an editorial letter:

- Stick to the point. Short, crisp sentences that lead directly to the point of the letter will get your letter noticed. Keep the length to 200-300 words.
- If possible, look to contrast your views with those expressed already in the editorial section.
- If you are responding to a letter or editorial, do it right away. The quicker you send in your response, the more likely it is to get published.
- Keep a neutral tone—be passionate, not rude.

BUILD COALITIONS – THERE'S STRENGTH IN NUMBERS!

The key to successful advocacy – in addition to finding the best means of contacting legislators and delivering your message – is building a coalition to amplify your voice and demonstrate popular support for your position. Nothing will get a legislator's attention quicker than receiving large numbers of telephone calls or letters from dozens of people, all saying the same thing.

Advantages to developing a coalition include diversity of message delivery, focus of message, more potential targets for your message, and shared costs.

- Key ingredients of successful coalitions include:
- Regular communication with members about current events and legislative happenings
- A key contact list
- Mobilized group that gets alerts for notifying members about upcoming legislative activity
- Outreach to new and different areas of support

There are many ways to build a personal coalition, starting with social media. Download our eAdvocacy Checklist, found at FightColorectalCancer.org, to get started!

MEET WITH LEGISLATORS

Many legislators hold "office hours" in their district on a regular basis so you can visit year-round! Many legislators depend on staff to meet with you to discuss concerns due to full schedules. And oftentimes, the staff is actually better informed on the details of the legislation and is very thorough at briefing the legislator on the content of your meeting. Tips for before, during, and after your meeting with your legislator can be found on page 17.

HOST AN EVENT

Fight Colorectal Cancer offers two ways to host an event in your town:

- **Town Hall Meetings:** A program launched in 2013, the Town Hall Meeting by Fight Colorectal Cancer brings advocacy training to YOU. Our meetings assemble survivors, caregivers and others touched by colorectal cancer to offer training on how advocacy works. It's a time for community members to meet one another, share stories, build coalitions and get fired up about colorectal cancer advocacy.

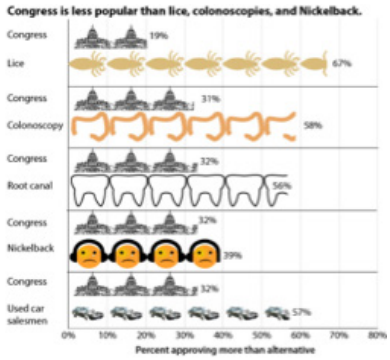
- **Million Strong March:** Need a way to bring the One Million Strong movement to your community? Host a Million Strong March! Our awareness events serve as an attention-builder for the cause and a fundraiser for Fight Colorectal Cancer.

Get more details at FightColorectalCancer.org.

HR 1070: PASSING A BILL IS NOT FOR THE FAINT OF HEART.

The current political climate on the Hill requires persistence if we want to make change.
The Affordable Care Act (ACA) seeks to improve access to colorectal cancer screening by waiving coinsurance, copays, and deductibles for many colorectal cancer screening tests. Screening tests include colonoscopies, sigmoidoscopies, and fecal occult blood tests (FOBT). This sounds simple in theory, but implementation is proving more challenging than expected.*

Fight Colorectal Cancer is actively working on policy changes that will reduce barriers for patients seeking screening services, including fixing some kinks in application of current law.
(Image source: **http://www.washingtonpost.com/blogs/wonkblog/wp/2013/01/10/graph-of-the-day-congress-is-less-popular-than-lice-colonoscopies-and-nickelback/***)*



Currently, there are 6,352 bills and resolutions before the U.S.Congress, of which about 5% will become law. *(Source: https://www.govtrack.us/congress/bills/)*

What does this mean for us?

Changing policy takes persistence. The average time for a bill to become law averages 3-5 years depending on the complexity of the legislation.

The ACA has generated unprecedented public debate and discussion over heath care vs. "sick care." Generally speaking, the American public supports policies that increase access to preventive services, including screenings.
In May 2012, the American Gastroenterological Association, American Society for Gastrointestinal Endoscopy, the American Cancer Society-Cancer Action Network (ACS CAN), National Colorectal Cancer Roundtable and Fight Colorectal Cancer met with officials from HHS and CMS to discuss this problem that Medicare patients face when receiving a screening colonoscopy.

Keep pushing and talking about this important issue. This is not easy work. It takes time, but you are doing the right thing by working together to fix this.

-Dr. Howard K. Koh, MD, MPH, currently serves as the 14th Assistant Secretary for Health for the U.S. Department of Health and Human Services.

As a coalition we lobbied for a correction, for both private payers and Medicare. HHS has the authority to make changes to commercial payers because it has broad regulatory authority. For this particular issue, CMS had argued it does not have the same broad authority to make changes to Medicare.

In the case of screening colonoscopies, the Obama Administration provided guidance to private insurers on application of cost-sharing requirements for private insurers (this excludes Medicare) by releasing an FAQ on Feb. 20, 2013, s (**http://www.dol.gov/ebsa/faqs/faq-aca12.html**) stating that if a screening colonoscopy is performed and a polyp is found and removed during the screening, then an insurer cannot impose cost-sharing since polyp removal is "an integral part of a colonoscopy."

Unfortunately, the devil is in the details. Insurers are now broadly interpreting the Feb guidance. Some are deciding that if a polyp is removed during a screening colonoscopy, any subsequent colonoscopy will be

considered a surveillance or diagnostic colonoscopy, not a screening colonoscopy. We are seeing variations in interpretation by state***. Physicians and the medical community require further education on appropriate billing and coding practices based on the guidance provided. At the end of the day, it boils down to how the medical's billing process defines and differentiates screening and diagnostic procedures.
Our first step is to address Medicare.

HR 1070: REDUCING BARRIERS TO COLORECTAL CANCER SCREENING

How does it reduce barriers to screening?

Many seniors are waking up from colonoscopies to an unexpected $100-$300 bill for a polyp removal (polypectomy). A polypectomy is standard practice during a screening colonoscopy, but the removal of the polyp(s) triggers a change in the classification of the service provided from a "screening" service to a "therapeutic" or "diagnostic" service under Medicare's billing codes. Knowing that a patient may wake up to an unexpected bill can create a significant barrier to fixed-income seniors who should have this potential life-saving screening. Congressman Charlie Dent (R-PA) introduced H.R. 1070 to amend current law so Medicare beneficiaries will not be liable for coinsurance when a polyp is removed during a screening colonoscopy.

"This is a glitch in the law that needs to be changed," said Rep. Dent. "We want more people to get colonoscopies. It is a life-saving screening procedure." This legislative fix will have a major impact on colorectal cancer screening, since almost 38 percent of U.S. adults age 50 and older have never been screened.

In the case of colorectal cancer screening, it is impossible to know whether a patient will have a polyp before the screening takes place. Patients should not be penalized for seeking screening when polyps are removed during the procedure.

It's time for change, and we're ready to fight for the long haul. Now is our time—we can make a difference.

There is a domino effect: CMS is a leader in the insurance industry

There are more than 42 million Medicare beneficiaries. Medicare is the largest healthcare insurer in the United States, making it an industry leader in coverage policies and standards. CMS contracts with numerous healthcare entities and thousands of providers and practices across the country to administer the Medicare program. In short, Medicare sets the standard for how billing is processed.

We know this oversight in current Medicare law has resulted in confusion and frustration for our seniors and for many who are privately insured. With the help of CMS, Medicare can lead the way toward standard, uniform cost-sharing practices for screening colonoscopies among private payers . It is imperative that CMS's leadership and members of Congress , understand this issue. The intent of the law is to encourage screening; however, when patients receive unexpected bills after undergoing a screening colonoscopy, it is seen as a penalty and disincentive.

Why does this require a bill?

CMS stated in the 2011 Medicare Physician Fee Schedule Final Rule** that legislative action is necessary to waive the beneficiary coinsurance for colorectal cancer screenings. So our FIRST step to passing corrective

legislation is to generate as many cosponsors of H.R. 1070 as possible.
You can be a part of the solution! ASK your Representative to cosponsor HR 1070, or thank him/her for already doing so.

To find contact information for your representative, visit **http://www.house.gov/representatives/find/**
To see the full list of cosponsors and a detailed description of the bill, visit
https://www.govtrack.us/congress/bills/113/hr1070.

**Coinsurance is the term used by health insurance companies to refer to the amount that you are required to pay for a medical claim, apart from any co-payments or deductible.*

***The Medicare Physician Fee Schedule Final Rule is an annual update to payment and payment policies for Medicare Part B services. ***For more on private insurance practices, Fight Colorectal Cancer joined the National Colorectal Cancer Roundtable, the American Cancer Society, The Kaiser Family Foundation, and stakeholders across the country to further examine this emerging cost barrier to colorectal cancer screening, in a report entitled, "COVERAGE OF COLONOSCOPIES UNDER THE AFFORDABLE CARE ACT'S PREVENTION BENEFIT," published in Sept. 2012.* **http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8351.pdf**

*****Here's the exact language provided by the government in their FAQ guidance document to private insurers:*
Q5: If a colonoscopy is scheduled and performed as a screening procedure pursuant to the USPSTF recommendation, is it permissible for a plan or issuer to impose cost-sharing for the cost of a polyp removal during the colonoscopy?

No. Based on clinical practice and comments received from the American College of Gastroenterology, American Gastroenterological Association, American Society of Gastrointestinal Endoscopy, and the Society for Gastroenterology Nurses and Associates, polyp removal is an integral part of a colonoscopy. Accordingly, the plan or issuer may not impose cost-sharing with respect to a polyp removal during a colonoscopy performed as a screening procedure. On the other hand, a plan or issuer may impose cost-sharing for a treatment that is not a recommended preventive service, even if the treatment results from a recommended preventive service.

ADDITIONAL RESOURCES TO BETTER UNDERSTAND THIS ISSUE

What about Medicaid?

The latest report from NCCRT, Coverage of Medicaid Preventive Services for Adults – A National Review, was the basis of an article published in Health Affairs this past summer.

The study intends to provide a better understanding of Medicaid coverage of preventive services for adults in the current state Medicaid programs and inform state policy makers as they consider the level of preventive benefits and services to offer should they expand Medicaid in 2014.

You may access the full report and the article abstract here:
http://nccrt.org/about/policy-action/a-national-review-medicaid-coverage/

For more on Federal and state colorectal cancer screening legislation:
http://www.cancer.org/cancer/colonandrectumcancer/moreinformation/colonandrectumcancerearlydetection/colorectal-cancer-early-detection-screening-coverage-laws

GLOSSARY OF TERMS

Commonly used terms in the Patient Protection and Affordable Care Act

Adjusted community rating — Adjusted community rating is between individual age rating (under which each person has their own premium), and pure community rating (under which there is only one premium applicable to all). "Adjusted community rating, allowing variation for age" permits rates that vary by age, but the highest premium cannot be more than double the lowest premium (2:1 max).

Annual limit — Many health insurance plans place dollar limits upon the claims the insurer will pay over the course of a plan year. Health reform prohibits annual limits for essential benefits for plan years beginning last fall.

Coinsurance — A percentage of a health care provider's charge for which the patient is financially responsible under the terms of the policy.

Community rating — A way of pricing insurance, where every policyholder pays the same premium, regardless of health status, age or other factors.

Essential benefits — Health reform requires all health insurance plans sold after 2014 to include a basic package of benefits including hospitalization, outpatient services, maternity care, prescription drugs, emergency care and preventive services, and other benefits. It also places restrictions on the amount of cost-sharing that patients must pay for these services.

Guaranteed issue — Guaranteed issue is the right to purchase insurance without a physical examination; the present and past physical condition of the applicant are not considered.

Health insurance exchange — Health insurance exchanges are entities that organize the market for health insurance by assembling individuals and small businesses into larger pools that spread the risk for insurance companies, while facilitating the availability, choice and purchase of health insurance.

Health Savings Account — The Medicare bill signed by President Bush on Dec. 8, 2003, created HSAs. Individuals covered by a qualified high deductible health plan (and have no other first dollar coverage) are able to open an HSA on a tax preferred basis to save for future qualified medical and retiree health expenses. Additional information about HSAs can be found on the U.S. Treasury Web site: **http://www.treas.gov/offices/public-affairs/hsa/**.

High risk pool — A state-subsidized health plan that provides coverage for individuals with pre-existing health care conditions who cannot purchase it in the private market. Health reform creates a temporary federal high risk pool program, administered by the states, to provide coverage to individuals with pre-existing conditions who have been uninsured for at least 6 months.

Individual mandate — A requirement that everyone maintain health insurance coverage. Health reform requires that everyone who can purchase health insurance for less than 8% of their household income do so or pay a tax penalty.

Lifetime limit — Many health insurance plans place dollar limits upon the claims that the insurer will pay over the course of an individual's life. Health reform prohibits lifetime limits on benefits beginning last fall.

Limited benefits plan — A type of health plan that provides coverage for only certain specified health care services or treatments or provides coverage for health care services or treatments for a certain amount during a specified period.

Long-term care insurance — Long-term care insurance provides coverage for the day-to-day care that a person receives in a nursing facility or in his or her residence following an illness or injury, or in old age, such that the person can no longer perform at least two of the five basic activities of daily living: walking, eating, dressing, using the bathroom and mobility from one place to another. Benefits paid under a long-term care insurance policy will typically be subject to a waiting period (for example, 90 days); a benefit period (for example, five years); and a daily amount (for example, $100 per day). The combination of these benefit provisions help to determine the premium to be paid for such a policy.

Mandated benefit — A requirement in state or federal law that all health insurance policies provide coverage for a specific health care service.

Medical loss ratio — The percentage of health insurance premiums that are spent by the insurance company on health care services. Health reform requires that large group plans spend 85 percent of premiums on clinical services and other activities for the quality of care for enrollees. Small group and individual market plans must devote 80 percent of premiums to these purposes.

Medicare Advantage — An option Medicare beneficiaries can choose to receive most or all of their Medicare benefits through a private insurance company. Also known as Medicare Part C. Plans contract with the federal government and are required to offer at least the same benefits as original Medicare, but may follow different rules and may offer additional benefits. Unlike original Medicare, enrollees may not be covered at any health care provider that accepts Medicare, and may be required to pay higher costs if they choose an out-of-network provider or one outside of the plan's service area.

Medicare Part D — Medicare offers prescription drug coverage for everyone with Medicare through this program. Medicare prescription drug coverage is obtained by joining a Part D plan (sometimes called PDPs) offered by an insurance company or other private company approved by Medicare. Each plan can vary in cost and drugs covered. In addition to obtaining Medicare prescription drug coverage by enrolling in a Part D plan, coverage also can be obtained by purchasing a Medicare Advantage plan, which includes prescription drugs as part of their benefit package (sometimes called MA-PDs).

Medicare Supplement (Medigap) Insurance — Private insurance policies that can be purchased to "fill-in the gaps" and pay for certain out-of-pocket expenses (like deductibles and coinsurance) not covered by original Medicare (Part A and Part B).

Patient Protection and Affordable Care Act (PPACA) — Legislation (Public Law 111-148) signed by President Obama on March 23, 2010. Commonly referred to as the health care reform law.

Preexisting condition exclusion — The period of time that an individual receives no benefits under a health benefit plan for an illness or medical condition for which an individual received medical advice, diagnosis, care or treatment within a specified period of time prior to the date of enrollment in the health benefit plan. PPACA prohibits pre-existing condition exclusions for all plans beginning January 2014.

Preventive benefits — Covered services that are intended to prevent disease or to identify disease while it is more easily treatable. Health reform requires insurers to provide coverage for preventive benefits without deductibles, co-payments or coinsurance.

Provider — A health care provider, most commonly referring to as a physician.

Qualified health plan — A health insurance policy that is sold through an Exchange. Health reform requires Exchanges to certify that qualified health plans meet minimum standards contained in the law.

Reinsurance — Insurance purchased by insurers from other insurers to limit the total loss an insurer would experience in case of a disaster or unexpectedly high claims. Health reform directs states to create temporary reinsurance programs to stabilize their individual markets during the implementation of health reform.

Rescission — The process of voiding a health plan from its inception usually based on the grounds of material misrepresentation or omission on the application for insurance coverage that would have resulted in a different decision by the health insurer with respect to issuing coverage. PPACA prohibits rescissions except in cases of fraud or intentional misrepresentation of a relevant fact.

Self-insured — Group health plans may be self-insured or fully insured. A plan is self-insured (or self-funded), when the employer assumes the financial risk for providing health care benefits to its employees. A plan is fully insured when all benefits are guaranteed under a contract of insurance that transfers that risk to an insurer.

Source: North Dakota Insurance Department and the National Association of Insurance Commissioners

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