Geisinger Project Begins to Yield Tangible Results from Genetic Data.

MyCode is a project that seeks to find "genetic contribution to illness; to advance knowledge of genomic medicine; and to provide new and improved treatments – and even possibly future cures – for disease." The initial program was developed out of an unusual situation. Through the rise of genetic sequencing, the ability to scan for "superhero genes" – those that actually prevent disease – has been somewhat successful. A few years ago, 13 individuals with gene mutations that protected them from severe illness were discovered through the *Resilience Project*. Unfortunately, the information was completely anonymous – preventing any further contact with the individuals. The anonymity of such an endeavor has been the "Achilles heel of genomic or precision medicine."

This need for patient participation and engagement spurred the creation of the MyCode Community Health Initiative by Geisinger Health System. Unlike previous projects, MyCode has the "permission to re-contact [participants] for further studies and evaluations." After the initial group of 115,000 participants, 148 have been found to hold "gene mutations associated with certain conditions or diseases and were therefore at risk of developing these diseases." With this discovery, and the protocols put in place, MyCode has been able to communicate with the participants directly to provide information and resources. The ability for conversation and interaction allows for the continuation of research into the effects of these "superhero genes." Hopefully, more projects like this will help lead the way on this exciting new research opportunity. *MyCode Community News,* Sept. 2016

Can the U.S. Repair Its Health Care While Keeping Its Innovation Edge?

Some fear that major changes in health care markets and policies will negatively affect American medical innovation. In an Oct. 9 *New York Times* article, authors Aaron E. Carroll and Austin Frakt attempt to clarify this relationship by first establishing America's leading role in health care innovation. "It has more clinical trials than any other country. It has the most Nobel Laureates in physiology or medicine. It has won more patents." They also highlight one publication's ranking of the U.S. as "No. 1 in overall scientific innovation."

After this defense of American ingenuity, the authors examine factors which most likely spur such a creative environment. One is the existence of a "first-class research university system." The existence of so many institutions of higher

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education produces researchers who have the knowledge and resources to embark on scientific explorations. Other major factors are America's "robust intellectual property laws and significant public and private investment in research and development." Along with the existence of a "large market in which patients, organizations and government spend a lot on health," authors recognize these factors as most important for the continuation of medical innovation.

The article also maintains that the U.S. can repair its health care while keeping its innovation edge. In fact, the authors argue that changes in payer source should not be our primary concern. With the knowledge of the factors that do promote innovation, we can instead focus on better ways to direct our financial resources. They conclude with a quote from Dr. Ashish Jha, director of the Harvard Global Health Institute, "We have confused the issue of how we pay for care – market-based, Medicare for all, or something else – with how we spur innovation. In doing so, we have made it harder to engage in the far more important debate: how we develop new tests and treatments for our neediest patients in ways that improve lives and don't bankrupt our nation." Aaron E. Carroll and Austin Frakt, *New York Times*: Oct. 9, 2017.
https://www.nytimes.com/2017/10/09/upshot/can-the-us-repair-its-health-care-while-keeping-its-innovation-edge.html

Young Victims of Opioid Crisis Pay High Price

Citing the story of a grandmother raising a 2-year-old grandson dependent on heroin, author Brian MacQuarrie in an Oct. 7 Boston Globe article outlines the tragic effects of the opioid crisis on children across Massachusetts. The child whose name is Mason was "born dependent on heroin…[his] two parents overdosed shortly into his young life." His mother survived, but father did not. Mason was placed into the custody of his grandmother.

This story is not uncommon. In fact, the article states, "since 2013, the average number of children and young adults in state custody has risen 26 percent to more than 9,200 in August." Meanwhile, "petitions to remove children from their homes rose 57 percent statewide from fiscal 2012 to fiscal 2016." Such a large increase has put a massive strain on an already overworked welfare system. To meet the demand, the Massachusetts' Department of Children and Families (DCF) has increased "its staff of social workers by 300" and added "about 140 new foster homes." Even with these increases, "caseloads remain at dangerously high levels in parts of the state, and that some children who should be removed from their homes might slip through the cracks."

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The crisis is still in its early phases. Some caution "that the epidemic's long-term impact will not be apparent until today's children become adults." Fortunately, Massachusetts Governor Charlie Baker has made child-welfare reform a "priority of his administration", adding $100 million to the DCF budget. It will take many years and many more millions to see this trend stop. Hopefully, more leaders will make it a priority of their own administrations. Brian MacQuarrie, *The Boston Globe*: Oct. 7, 2017.
https://www.bostonglobe.com/metro/2017/10/07/children-are-lesser-known-victims-opioid-crisis/1D4lkN2kmEzeApqJ1g3BPI/story.html

What I Learned From Organizing, Participating in Boston's 'Amoris Laetitia' Event

Fr. James Keenan, SJ and Cardinal Blase Cupich of Chicago sponsored a seminar, October 5-6 2017, on Pope Francis' apostolic exhortation, *Amoris Laetitia* at Boston College. Notable participants of church leaders and experts included Cardinal Kevin Farrell (prefect of the Dicastery for Laity, Family and Life), Malta Archbishop Charles Scicluna (canonist), and Jesuit Fr. Antonio Spadaro (editor of Civiltà Cattolica).

The schedule included "five panels, each one with three or four presenters" followed by an hour-long discussion. Fr. Keenan shared a few "significant catch phrases for describing the style and content of our seminar." The first was from theologian, Lisa Sowle Cahill of Boston College who remarked, "It's so good that the speakers basically chose to describe the contemporary situation in terms of families, instead of marriages." Keenan noted that this shift in focus helped to prevent the common sidetracking of the conversation towards "the politics of marriage."

Another notable moment Keenan noted was a "much repeated claim" that "we have discovered that there are eight chapters to *Amoris Laetitia.*" What may seem like an obvious "discovery" attempts to counter the general focus by the public and church leaders on "footnote 351 that mentions the 'help of the sacraments' for divorced and remarried Catholics…" The recognition and general attention on the whole document allowed the participants to gain "a profound appreciation of the challenges felt by families in the United States." Anyone who has had the opportunity to read the document in its entirety will discover the depth of connection Pope Francis has with the difficulties facing many in the church. By responding to the needs of the family, Pope Francis has called us all to witness to "the church that Francis is inviting us to be." A future publication synthesizing the conversations will be published by Paulist Press. James Keenan, *The National Catholic Reporter*: Oct.

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9, 2017.
https://www.ncronline.org/news/opinion/what-i-learned-organizing-participating-bostons-amoris-laetitia-event

Artworks that Teach Faithful How to Die Well

Bowdoin College Museum of Art is showcasing works from around 1500 C.E. What is unique about these pieces is their genre, "memento mori." Some may remember hearing this term in a theology course. It is a "Latin admonition to remember that everyone must die." One piece on display includes "two pages from the 1466 German book *Ars Moriendi* ('The Art of Dying Well') which depict a dying man surrounded by angels and demons. The figures attempt to persuade the man from willing all his possessions to his family, and instead to give some to the church and to charity.

Barbara Boehm, senior curator for the Met Cloisters, states "the best memento mori images stop us in our tracks…and cause us to think about what we are doing with our lives, what kind of legacy we will leave." These images, statues, and manuscripts attempt to "illustrate moral values." However, they "cannot be considered wholly outside theology." By highlighting this exhibition, the author of this article wants to clear some misunderstandings about the memento mori tradition, and the theological debates going on during the 16th century. It is an interesting take on the relationship between expressions of art and the public conversation at the time of its creation. Menachem Wecker, *The National Catholic Reporter*: Oct. 10, 2017.
https://www.ncronline.org/news/media/artworks-teach-faithful-how-die-well

STAT List: These 10 Cities Had the Biggest Jumps in Hospital Jobs

Data from the U.S. Census Bureau and Bureau of Labor Statistics from July 2007 to July 2017 examine gains in hospital employees among the top 100 largest metropolitan areas. The top five cities with most gains in hospital employees are: New Orleans at 78 percent; Boise, Idaho at 72 percent; Austin, Texas at 51 percent; Columbus, Ohio at 51 percent; and Bakersfield, California at 49 percent. This rise in health care fields has been "a main driver of employment gains since the Great Recession." However, "there's a risk too: If the country ever actually tries to control health care costs, it won't be able to support as many jobs in the industry." Andrew Joseph, *STAT News:* Oct. 11, 2017. https://www.statnews.com/2017/10/11/10-cities-hospital-jobs-jump/

Students from the Saint Louis University School of Law Center for Health Law Studies contributed the following items to this column. Amy N. Sanders, associate director, supervised the contributions of Drew

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Canning (J.D. anticipated 2018) and Merlow Dunham (J.D./MHA anticipated 2019).

Appeal of Medicare Payment Rule Splits Circuits and Benefits Hospitals

The U.S. Court of Appeals for the District of Columbia Circuit determined that a Medicare payment rule impacting Disproportionate Share Hospitals was not exempt from standard notice and comment procedures. The payment rule counted Medicare Advantage patients as entitled to Part A benefits, thereby reducing reimbursement for indigent care, and was effective 2014. However, Health and Human Services (HHS) disregarded public notice and comment, arguing the payment rule was exempt under the Administrative Procedure Act's (APA) interpretive rule provision. Breaking with the First, Sixth, Eighth and Tenth Circuit, the D.C. Circuit, through Judge Brett Kavanaugh's opinion, stated the APA exception does not apply to the Medicare Act. Additionally, the D.C. Circuit split with the 9th Circuit on the issue of reviewability of expedited judicial review orders granted from the Provider Reimbursement Review Board (PRRB). In the July 25th ruling, the D.C. Circuit found providers are guaranteed expedited judicial review when the PRRB determines they have no authority to hear the appeal. HHS may decide to pursue a rehearing with the D.C. Circuit, petition the U.S. Supreme Court, or implement the appeals court ruling. If the ruling were to stay, it would potentially eliminate some of PPRB's appeals backlog as well as increase provider appeals within D.C. federal court. Eric Topor, *BNA,* July 26, 2017 https://www.bna.com/hospitals-score-big-n73014462411/

Problem Solvers Caucus Hopes to Secure Health Exchange Market

Forty-four House of Representative members, named the Problem Solvers Caucus, are moving forward to "restore predictability" for insurance companies participating in the health exchanges. The 22 Republicans and 22 Democrats are petitioning committees that oversee areas of the Affordable Care Act to address key issues of stability. The bipartisan group's top goal is to appropriate reimbursement to insurance companies for covering low-income customers at reduced cost-share rates. The cost-share reduction funds have been challenged since 2014 when House Republicans withheld payments to health plans and successfully sued the executive branch. Other items include sending money to states for reinsurance programs, applying the employer mandate to companies with 500 employees or more, and improving guidance on section 1333, which allows

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insurers to sell health plans across state lines upon the agreement of state regulators. Currently the employer mandate impacts companies with 50 or more employees. Mara Lee, *Modern Healthcare*, July 31, 2017
http://www.modernhealthcare.com/article/20170731/NEWS/170739986/bipartisan-coalition-looks-to-solve-problem-of-individual-market

Cities Lose Health Marketplace Enrollment Support for 2018

The Centers for Medicare and Medicaid Services (CMS) withdrew in-person health insurance enrollment support offered by two companies, McLean and CSRA Inc., for the 2018 marketplace open enrollment. The decision follows similar administration decisions such as implementing a shorter 45-day open enrollment period, as opposed to 90 days, and cancelling advertising for the health insurance sign-up website HealthCare.gov. McLean and CSRA Inc. were awarded contracts in 2013 and operated in 18 cities, focusing on sign-up assistance in libraries, business, and urban neighborhoods. The contracts contained a final option year which CMS elected not to renew and each will end services on August 29th. CMS continues to have a year-round call center and grant-funded sign-up programs. Impacted cities include Dallas, Houston, Miami, Tampa, Atlanta, Philadelphia, Chicago, Cleveland, New Orleans, Indianapolis, Charlotte, San Antonio, Austin, El Paso, Orlando, Phoenix, and Northern New Jersey. Carla K. Johnson, *The Washington Post*, July 20, 2017
http://wapo.st/2gNrtqr?tid=ss_mail&utm_term=.a436ea15b94f

E-Cigarette Regulation Delayed, FDA Focuses on Nicotine

FDA Commissioner, Dr. Scott Gottlieb, announced a holistic approach to reduce tobacco deaths and nicotine addiction while postponing e-cigarette rules that would have required product approval. Public input will be sought to lower nicotine levels in combustible cigarettes to non-addictive levels. However, the commissioner remains suspect of e-cigarette flavors aimed at children, such as Tutti Frutti and Banana Mash, and will consider regulation. Tobacco is the leading cause of preventable death, contributing to over 480,000 deaths a year, and the FDA views e-cigarettes as a possible cessation device because the vapor does not contain tar and other chemicals. The Tobacco Vapor Electronic Cigarette Association issued support for the new approach as well as the parent companies of Marlboro and R.J. Reynolds, for which the former called the announcement "an important evolution in the agency's approach to

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regulating tobacco." Sheila Kaplan, *New York Times*, July 28, 2017
https://www.nytimes.com/2017/07/28/health/electronic-cigarette-tobacco-nicotine-fda.html

Medical Debt Will Have Delayed and Reduced Impact on Credit Score

Beginning September 15, Experian, Equifax, and TransUnion will institute a 180-day waiting period before medical debt appears on consumers' credit report. Also, the three major credit reporting agencies will remove medical debt from credit reports when it is paid by insurers. These updates arrive as FICO's newest credit-scoring model differentiates medical and non-medical debt, with the latter receiving smaller penalties in scoring. The change by credit reporting agencies originates from a settlement with New York Attorney General Eric Schliemann as well as agreements with 31 state attorneys general to aid the 42 million consumers with medical debt. The Financial Hope Collaborative at Creighton University indicated that "without a standardized process, some bills get sent to collections because they're 30 or 60 days past due." Additionally, the Financial Protections Bureau listed $579 as the average medical debt in collections. Michelle Andrews, *Kaiser Health News*, July 11, 2017
http://khn.org/news/your-credit-score-soon-will-get-a-buffer-from-medical-debt-wrecks/

Hospital Systems Await States' Approval for Monopoly, Avoid FTC

Mountain States Health Alliance and Wellmont Health Systems, both located along the Tennessee and Virginia border, await those states' approval of their merger that would create a thirteen-county monopoly on health services. The attempted merger would avoid Federal Trade Commission scrutiny by utilizing a Certificate of Public Agreement (COPA) available in the states of Virginia and Tennessee. Their plan requires regulators in each state to determine if the merger is in the public interest and then each state would govern parts of the company going forward, including price setting. Revenue gained from the combined entity would need to be used on public health concerns such as obesity and smoking. Since the 1940s, COPA use in hospital mergers has occurred less than 14 times, including in nearby Asheville, North Carolina and last summer in West Virginia. Studies by economists indicate consolidation means higher prices, however Mountain States and Wellmont argue the merger will allow them to focus on care the community needs as opposed to services that produce highest profits. The FTC has condemned the plan by dismissing promises made by the companies and

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indicating many of the health systems goals can be achieved without the merger. Likewise, area residents question the move. About 17,000 employees await the COPA decision. Phil Galewitz, *Kaiser Health News*, July 24, 2017 http://khn.org/news/in-appalachia-two-hospital-giants-seek-state-sanctioned-monopoly/

Judge Strikes Down Alabama Law Putting Pregnant Minors Through Trial

A federal magistrate judge held that a unique law in Alabama imposes "an undue burden" on girls seeking permission to have an abortion through a judicial bypass procedure, wherein a minor who lacks parental permission for an abortion can instead obtain a court's permission. The judicial bypass is a trial-like proceeding where a judge may appoint a guardian *ad litem* to represent the interests of the fetus, and the minor is questioned in court to determine whether she is mature enough to make an informed decision to have an abortion without parental consent. The judge sided with the American Civil Liberties Union of Alabama, which argued that because a judicial bypass enables state attorneys to subpoena the girl's teachers, friends, family, etc. to testify about her maturity, the girl's right to confidentiality is violated and she is exposed to potential physical and mental abuse once her wish to abort is made known to others in her life. The judge noted that she knew of no other state with such a law. The Associated Press, *The New York Times*, July 31, 2017 *https://www.nytimes.com/aponline/2017/07/31/us/ap-us-abortion-law-alabama.html?utm_campaign=KHN%3A%20First%20Edition&utm_source=hs_email&utm_medium=email&utm_content=54831764&_hsenc=p2ANqtz-9-1WZ7zTe8FkQr53QXj7rH6Sv6Hlr7lSiHK_2MoqIvW-b-WfF6FnUzrwSiuU1M401RMJfIHhddw8rnqi_rHCTUyac3oA&_hsmi=54831764*

Trump Cites Health Care Costs Among Reasons for Not Allowing Transgender People in the Military

President Donald Trump announced that transgender individuals will no longer be allowed to serve in the United States military out of concern for "tremendous medical costs and disruption" that would result. The declaration via Twitter was made in response to a dispute over whether taxpayer money should be used to pay for gender transition and hormone therapy for service members who identify as transgender. A 2016 RAND Corporation study commissioned by the Pentagon estimates that between 2,000 and 11,000 active-duty service members are transgender. This same study concluded that openly transgender service

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members would increase health care costs from $2.4 million to $8.4 million, a mere 0.04 to 0.13 percent spending increase. While some conservative lawmakers have supported the president, many civil rights and transgender advocacy groups have expressed outrage and the president's decision is likely to end up in court. Julie Hirschfeld Davis and Helene Cooper, *The New York Times*, July 26, 2017*https://www.nytimes.com/2017/07/26/us/politics/trump-transgender-military.html*

World Health Organization Releases New List of "Reserve" Antibiotics, Used to Combat Superbugs

The World Health Organization (WHO) released new categories of antibiotics in an effort to increase the reserve of "last resort" drugs used to combat superbugs. WHO cites overuse of antibiotics in humans and livestock as the main reason behind the increasing number of new pathogen strains that are resistant to traditional antibiotics. The WHO advises that antibiotics are placed in one of three categories – access, watch, and reserve – to designate which drugs can be used more regularly and which should only be used as a "last resort." The "access" category includes common antibiotics like amoxicillin that should be "available at all times." The "watch" category includes antibiotics such as ciprofloxacin that should only be used when needed. The third "reserve" category includes antibiotics like colistin that are the last line of defense and should only be used "in the most severe circumstances when all other alternatives have failed." The newly-categorized lists of antibiotics can be found in the WHO's Model Lists of Essential Medicines for 2017, which is revised every other year to provide guidelines for the drugs that each country should keep in stock. Ariana Eunjung Cha, *Modern Healthcare*, June 6, 2017 *https://www.washingtonpost.com/news/to-your-health/wp/2017/06/06/who-creates-controversial-reserve-list-of-antibiotics-in-new-response-to-superbug-threats/?tid=a_inl&utm_term=.370c9bd6c9d4*

Accountable Care Organizations and Alternative Payment Models Grow in 2017

A recent *Kaiser Health* study shows that accountable care organizations (ACOs) and alternative payment models (APMs) continue to grow in 2017. In the past year in the United States, there was an increase in 2.2 million lives covered by an ACO, meaning over ten percent of the population is currently covered by an ACO. Commercial ACO contracts tend to cover the most lives (715 contracts, 59 percent of covered lives), followed by Medicare contracts (563 contracts, 29 percent of covered lives), followed by Medicaid contracts (88 contracts, 12 percent of covered lives). ACOs currently exist

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in every state, including Washington D.C. and Puerto Rico. Similarly, there has been increased growth in APMs, likely due to the passage of the Medicare Access and CHIP Reauthorization Act (MACRA), which provides incentives for physicians to join APMs. The majority of APM participants are involved in the medical home model (2891 participants), followed by the episode-based model (792 participants), followed by the ACO model (480 participants in traditional Medicare Shared Savings Program ACOs, and 45 participants in Next Generation ACOs). David Muhlestein et al., *Health Affairs*, June 28, 2017 *http://healthaffairs.org/blog/2017/06/28/growth-of-acos-and-alternative-payment-models-in-2017/*

Veterans Health Administration Proves Successful in Increasing Veterans' Hospice Use

The Comprehensive End of Life Care Initiative, a four-year investment implemented in 2009 by the Department of Veterans Affairs (VA) aimed at improving the quality of end-of-life care for veterans, has proven to be effective as reflected by increased hospice use. In the first two years following implementation, the initiative resulted in the establishment of 54 new hospice and palliative care inpatient units. A recent study published in *Health Affairs* shows that the initiative successfully increased rates of hospice use among male veterans age 66 and older. The initiative's impact has been felt beyond the VA system, as it also resulted in over 3,000 community hospices making commitments to improve the quality of end-of-life care for veterans. This study confirms the impact that the VA system can have on increasing the quality of end-of-life care for veterans, even within a short duration of time. Susan C. Miller et al., *Health Affairs*, July 2017 *http://content.healthaffairs.org/content/36/7/1274*

THE 2018 HASTINGS CENTER CUNNIFF-DIXON PHYSICIAN AWARDS

2018 NOMINATION CALL

Suggest Your Nominees for the 2018 Awards

The Hastings Center Cunniff-Dixon Physician Awards are presented to recognize and support excellence in care near the end of life.

Prizes in the amount of $25,000 will be awarded to a senior physician (20+ years in practice) and $25,000 to a mid-career physician (8-19 years in practice) who have demonstrated an exemplary commitment to patients near the end of life through their doctoring, research, and/or service to their community.

Three additional awards in the amount of $15,000 each will go to early-career physicians (0-7 years) who have already demonstrated exemplary efforts with patients near the end of life.

Nominations for 2018 are due by December 31, 2017

More information can be found at

http://physicianawards.org

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