

## American Nephrology Nurses Association

Weekly Capitol Hill Update – Tuesday, May 29, 2018

### Congressional Schedule

#### Senate

- Senate is out of session – Congress returns next week.

#### House

- House is out of session – Congress returns next week.

### Legislative Update

- **Week in Review**

- *House passes 'Right-to-Try' bill for experimental drugs.* “Legislation that would allow terminally ill patients to get access to experimental drugs is headed to the president's desk. The House on Tuesday passed a ‘right-to-try’ bill that was approved by the Senate in 2017. Advocates say the bill would make it easier for patients to get access to experimental drugs that have completed the first phase of clinical trials and are in the midst of additional testing. It eliminates the role of the Food and Drug Administration in the approval process and reduces the threshold for patients to receive the medicines. Critics say that removing the FDA from the process could raise the risks for patients.”
  - Read more: <https://www.npr.org/sections/health-shots/2018/05/22/613106777/house-passes-right-to-try-bill-for-experimental-drugs>
- *Dem senators ask drug companies to list prices in ads.* “A group of mostly Democratic senators is urging eight major drug companies to include the price of their drugs in advertisements, a measure that President Trump endorsed last week in his drug-pricing blueprint. The letter was sent to major pharmaceutical companies such as Eli Lilly, Novartis and Pfizer.”
  - Read more: <http://thehill.com/policy/healthcare/388367-dem-senators-ask-drug-companies-to-voluntarily-list-prices-in-ads>
- *GOP Chairman in talks with 'big pharma' on moving drug pricing bill.* “Sen. Chuck Grassley (R-Iowa) said Monday he is in talks with drug companies about

a possible deal to pass a drug-pricing bill in exchange for separate action that the companies want. Grassley told reporters that he is in talks with "Big Pharma" about using the savings from passing that bill to fund other priorities that drug companies want, likely a reference to a separate fix that drug companies have been pushing for to reduce their costs in Medicare."

- Read more: <http://thehill.com/policy/healthcare/388692-gop-chairman-in-talks-with-big-pharma-on-moving-drug-pricing-bill>

- *Senate sends major VA reform bill to Trump's desk.* "The Senate easily cleared legislation on Wednesday overhauling medical care options for veterans, sending the bill to President Trump's desk. Senators voted 92-5 on the proposal, called the VA Mission Act, with only a simple majority needed to pass the bill. Sens. Bernie Sanders (I-Vt.), Brian Schatz (D-Hawaii), Jeff Merkley (D-Ore.), Mike Rounds (R-S.D.) and Bob Corker (R-Tenn.) voted against the legislation."

- Read more: <http://thehill.com/homenews/senate/389072-senate-sends-major-va-reform-bill-to-trumps-desk>

- **Week Ahead**

- *Greg Walden predicts opioid bills coming to House by middle of June.* "The House likely will take up 57 bills to combat the opioid crisis by the middle of June, the chairman of the House Energy and Commerce Committee said Tuesday. Rep. Greg Walden, R-Ore., said work is being done now to prepare the 57 bills for the House floor. The panel advanced the legislation out of committee during a marathon markup session last week. Walden didn't give a specific date for when the bills will reach the House floor. But he estimated that the House would take up the bills by the middle of June."

- Read more: <https://www.washingtonexaminer.com/policy/healthcare/greg-walden-predicts-opioid-bills-coming-to-house-by-middle-of-june>

- *Senate panel heading toward June hearing for Trump's next VA pick.* "Sen. Johnny Isakson (R-Ga.), the chairman of the Senate Veterans' Affairs Committee, signaled on Tuesday that his panel will take up acting Veterans Affairs Secretary Robert Wilkie's nomination to lead the department next month. 'For all of your information, Jon and I have talked, I intend to move to have a committee meeting when we come back from the Memorial Day break as soon as I can,' Isakson told reporters at a press conference, referring to committee ranking member Jon Tester (D-Mont.). The Senate is expected to leave town by Friday for a weeklong break and return to Washington in early June."

- Read more: <http://thehill.com/homenews/senate/388836-senate-panel-heading-toward-june-hearing-for-trumps-next-va-pick>

- *Senate panel to consider ban on prescription drug 'gag clauses'.* "The Senate health committee plans to vote on a bill next month banning "gag clauses" that can hide potential savings on prescriptions from consumers at the pharmacy counter. Committee Chairman Lamar Alexander (R-Tenn.) said Tuesday he hopes the panel will vote on the bill, authored by Sen. Susan Collins (R-Maine),

June 20. Specifically, Collins's bill would ban clauses in contracts between pharmacies, insurers and middle men that keep pharmacies from proactively telling customers they could save money on a prescription if they paid out of pocket instead of through insurance. It would apply to plans offered through the individual market and by private employers."

- Read more: <http://thehill.com/policy/healthcare/388981-senate-panel-to-consider-ban-on-prescription-drug-gag-clauses-next-month>
- ***Senate Finance Committee releases 22 opioid bills to mark up in 'coming weeks'.*** "The Senate Finance Committee released 22 bipartisan bills aimed at curbing the opioid epidemic, with plans to mark up the legislation in the "coming weeks," the panel announced Wednesday. The legislation is aimed at tackling the epidemic through the committee's jurisdiction, mainly in Medicare, Medicaid and human services. The Finance Committee is one of several panels working on legislation aimed at stemming the tide of the opioid epidemic, which is contributing to an estimated 115 American deaths per day according to the Centers for Disease Control and Prevention."
  - Read more: <http://thehill.com/policy/healthcare/389083-senate-finance-committee-releases-22-opioid-bills-aims-for-mark-up-in>
- ***Senate health committee to hold hearing on Trump drug pricing plan.*** "President Trump's top health official will testify at a Senate hearing next month about the president's proposal to reduce prescription drug costs. Health and Human Services Secretary Alex Azar will testify at the June 12 Senate Health, Education, Labor and Pensions Committee hearing, the first time lawmakers will publicly examine Trump's plan, which was unveiled earlier this month."
  - Read more: <http://thehill.com/policy/healthcare/medical-devices-and-prescription-drug-policy/389184-senate-health-committee-to>

### **Regulatory and Administration Update**

- ***Trump official on defensive as critics scoff at drug plan.*** "President Trump's health chief is struggling to show that the administration is serious about taking on drug companies after its proposals for lowering prices last week left big companies relieved and even spurred an uptick in their stock prices. Secretary of Health and Human Services Alex Azar insists that the companies are misreading the administration's plan and that it will bring down drug prices. Yet drug stocks rose after Trump's plan did not include most of the immediate actions that the industry had feared."
  - Read more: <http://thehill.com/policy/healthcare/388408-trump-official-on-defensive-as-critics-scoff-at-drug-plan>
- ***FDA plans to speed path to approval for some gene therapies, starting with hemophilia.*** "The Food and Drug Administration will soon be alerting companies that certain gene therapies in development can qualify for less arduous review at the agency, Commissioner Scott Gottlieb said Tuesday. Specifically, gene therapies for hemophilia, a rare disease in which blood doesn't clot properly because it lacks certain proteins, could

be evaluated based on whether therapy increases those proteins in the blood, regardless of whether the therapy actually causes the patient to bleed less.”

- Read more: <https://www.statnews.com/2018/05/22/fda-gene-therapy-hemophilia/>
- ***Trump spending cuts allowed to target kids' health insurance.*** “The Government Accountability Office on Tuesday delivered a victory to the Trump administration by greenlighting a proposal to claw back more than \$7 billion in unused cash from the Children’s Health Insurance Program. In a report sent to congressional offices Tuesday morning, the GAO approved the vast majority of the administration’s \$15.3 billion plan to cancel spending. With that legal approval, the White House’s plan for so-called rescissions will likely retain its filibuster-proof powers in the GOP-controlled Senate, easing the way for potential passage with a simple majority vote.”
  - Read more: <https://www.politico.com/story/2018/05/22/trump-spending-cuts-kids-health-insurance-559137>

### **Articles of Interest**

- ***Routine DNA screening moves into primary care.*** “If you have a genetic mutation that increases your risk for a treatable medical condition, would you want to know? For many people the answer is yes. But typically such information has not been a part of routine primary care. For patients at Geisinger Health System, that could soon change. Starting in the next month or so, the Pennsylvania-based system will offer DNA sequencing to 1,000 patients, with the goal of eventually extending the offer to all 3 million Geisinger patients.”
  - Read more: <https://www.npr.org/sections/health-shots/2018/05/22/613090774/routine-dna-screening-moves-into-primary-care>
- ***Dova Pharma's blood disorder drug gets FDA approval.*** “The U.S Food and Drug Administration said on Monday it had approved Dova Pharmaceuticals Inc’s drug to treat low blood platelet count in chronic liver disease (CLD) patients, who are scheduled to undergo a medical procedure. The drug to treat thrombocytopenia belongs to a class of treatments called thrombopoietin receptor agonists (TPO RA), which stimulate platelet production, and is the first such treatment to be approved by the FDA for CLD patients.”
  - Read more: <https://www.reuters.com/article/us-dova-pharms-fda/dova-pharmas-blood-disorder-drug-gets-fda-approval-idUSKCN1IM1QQ>
- ***Public support for vaccines drops a bit.*** “Support for vaccination has fallen a little among Americans in the past 10 years, a new survey out Monday finds. While almost all Americans still vaccinate their children on schedule and support doing so, the percentage who say they strongly support vaccination and who are firmly confident in vaccine recommendations has fallen, the survey by Research America found.”
  - Read more: <https://www.nbcnews.com/health/health-news/public-support-vaccines-drops-bit-n876156>

- ***Are you and your primary care doc ready to talk about your DNA?*** “If you have a genetic mutation that increases your risk for a treatable medical condition, would you want to know? For many people the answer is yes. But such information is not commonly part of routine primary care. For patients at Geisinger Health System, that could soon change. Starting in the next month or so, the Pennsylvania-based system will offer DNA sequencing to 1,000 patients, with the goal to eventually extend the offer to all 3 million Geisinger patients. The test will look for mutations in at least 77 genes that are associated with dozens of medical conditions ranging from heart disease to cancer, as well as variability in how people respond to pharmaceuticals based on heredity.”
  - Read more: <https://khn.org/news/are-you-and-your-primary-care-doc-ready-to-talk-about-your-dna/>
- ***Creating the new gold standard for health and well-being in cities.*** “CityHealth offers the 2018 updated assessment of how our nation’s 40 largest cities fare when it comes to policies that can make real, lasting impacts in people’s everyday quality of life. All of our recommendations are based in evidence, backed by experts, and have a track record of bipartisan support. Learn what’s happening in a city near you.”
  - Read more: <http://www.cityhealth.org/>
- ***With death rate up, US life expectancy is likely down again.*** “The U.S. death rate rose last year, and 2017 likely will mark the third straight year of decline in American life expectancy, according to preliminary data. Death rates rose for Alzheimer’s disease, diabetes, flu and pneumonia, and three other leading causes of death, according to numbers posted online Wednesday by the Centers for Disease Control and Prevention. Full-year data is not yet available for drug overdoses, suicides or firearm deaths. But partial-year statistics in those categories showed continuing increases.”
  - Read more: <https://apnews.com/93e1734d8d7f445cad4d1b72a8dd78bc/With-death-rate-up,-US-life-expectancy-is-likely-down-again>
- ***Drugmakers blamed for blocking generics have jacked up prices and cost U.S. billions.*** “Makers of brand-name drugs called out by the Trump administration for potentially stalling generic competition have hiked their prices by double-digit percentages since 2012 and cost Medicare and Medicaid nearly \$12 billion in 2016, a Kaiser Health News analysis has found. As part of President Donald Trump’s promise to curb high drug prices, the Food and Drug Administration posted a list of pharmaceutical companies that makers of generics allege refused to let them buy the drug samples needed to develop their products. For approval, the FDA requires so-called bioequivalence testing using samples to demonstrate that generics are the same as their branded counterparts.”
  - Read more: <https://khn.org/news/drugmakers-blamed-for-blocking-generics-have-milked-prices-and-cost-u-s-billions/>
- ***Delayed hospice care common for dialysis patients.*** “Very few Medicare patients on dialysis receive hospice care at the end of life, and when they do, they’re often enrolled too briefly to fully benefit from these services, a U.S. study suggests. Medicare, the U.S. health insurance program for the elderly that also covers Americans with kidney failure, will not pay for dialysis and hospice at the same time. This forces terminally ill patients to choose between continuing on dialysis or accessing hospice care, which may provide

more comfort and support at the end of life, researchers note in JAMA Internal Medicine. For the current study, researchers examined data on more than 770,000 dialysis patients covered by Medicare who died between 2000 and 2014. Overall, just one in five were receiving hospice services when they died.”

- Read more: <https://www.reuters.com/article/us-health-kidneyfailure-hospice-costs/delayed-hospice-care-common-for-dialysis-patients-idUSKCN11O3AE>

- ***Swallow this: a sensor could monitor gut health via engineered bacteria - and beam results to a smartphone.*** “Researchers have devised a new way to get a sneak peek into what’s going on deep in your digestive system, creating a swallowable sensor that, with the help of engineered bacteria and a tiny electrical circuit, can detect the presence of molecules that might be signs of disease and then beam the results to a smartphone app. The device, which scientists validated in pigs, remains a prototype and needs to be refined before it could be used in people. But the researchers, who reported their work Thursday in the journal Science, combined innovations in synthetic biology and microelectronics to create a modular platform that could be adapted to identify a wide range of molecules.”

- Read more: <https://www.statnews.com/2018/05/24/swallow-sensor-gut-smartphone/>