MGFA E-Update
April 2017

MGFA News

MGFA Launches New Foundation Focus Magazine – "Focus on MG"

The MGFA has launched a new newsletter with a new name as "Foundation Focus" has become "Focus on MG," and the Spring 2017 edition is available at:

LINK

MGFA's inaugural Circle of Strength is also introduced in this year's first issue. The MGFA would like to extend a special thank you to those who generously gave $1,000 or more in 2016. These supporters are now members of our Circle of Strength are included in the newsletter. The MGFA is excited about the new look of our newsletter, and we hope you enjoy the new publication as our organization continues to serve people who have MG, families and caregivers and strives to find a cure for Myasthenia Gravis.

Empire TV Show Star Deals With MG; Columnist Cites MGFA in Article

The entire first season of Empire was centered on Lucious Lyon slowly dying of ALS and having to choose a son to be his successor. But as it turns out, Lucious has Myasthenia Gravis instead. As the show continues to evolve, several columnists and reporters have mentioned

MG being discussed on the TV show, including one recent columnist on bustle.com who cited the MGFA: "According to Myasthenia.org, myasthenia gravis is "a chronic autoimmune neuromuscular disorder that is characterized by fluctuating weakness of the voluntary muscle groups." That explains why doctors thought that Lucious' muscle weakness was ALS and not MG, but it doesn't explain (yet, at least) why Lucious is in bed with a breathing apparatus strapped to his face. Perhaps his MG is acting up, because the myasthenia website lists "difficulty breathing" as one of the common symptoms, along with "weakness in the arms and legs" and "chronic muscle fatigue."
Click here to read more

First Eight MG Walks of 2017 Raise More Than $300,000

The first eight MG Walks in 2017 have raised more than $300,000 of the $900,000 goal for this year. Walks have taken place in Hawaii, Tampa Bay, Georgia, Tallahassee, South Florida, New Orleans, South Carolina and North Carolina. Since the inception of the MG Walks in 2011, more than four million dollars has been raised to help raise awareness, find a cure and fund patient services.

Here are the upcoming MG Walks:

DATE	CITY	LOCATION
May 6	Southern Wisconsin	Sheridan Park, Cudahy, WI
May 6	Northern Wisconsin	Pamperin Park, Green Bay, WI
May 6	New England	Pope John Paul II Park, Boston, MA

For more information and to register for these Walks visit www.mgwalk.org

The MG Walk campaign is dedicated to creating awareness, renewing hope and generating a vast network of community and support, all while raising critical funds for the Myasthenia Gravis Foundation of America. Mayor Denis Shortal supported the 5th annual Myasthenia Gravis Walk in March at the Brook Run Park in Dunwoody,

GA. Mayor Shortal became the first mayor to open a Myasthenia Gravis Walk. The local MG chapter was delighted to have the mayor's support and looks forward to seeing him at future events. Mayor Shortal is pictured with Dawn Warner, captain of the first place team Dream Vacations. LINK

MGFA Provides Tips on Taking Summer Vacations

As we head into the Summer, the time when most people take vacations, some in the MG Community may be wondering how to maximize comfort and safety while still having a change of scenery, relaxation and maybe even a little adventure.

Here are a few resources you may find helpful:

- In a new book we learn how Florida resident Terry Scott Cohen, 42, who gets about in a motorized scooter, has not let his myotonic dystrophy, a disease involving progressive muscle loss, get the best of him. He and his father, Barry M. Cohen, 72, a retired industrial psychologist, act as travel companions, and together the two Floridians have written a book, "Travel Near & Travel Far: Step Out of Your Disabled World!" That book was recently reviewed by the New York Times. Barry provides both encouragement for disabled travelers and practical advice on navigating the world from a scooter or wheelchair. The book is from WishingUWell Publishing. It's available through Amazon and Barnes & Noble among other sources. You can find a brief review through www.christopherreeve.org and a link to the New York Times review here:
  Click here to read more

Other resources on travel include:

- An article on traveling in Europe for those with special challenges. You can find it at https://www.ricksteves.com/travel-tips/trip-planning/travelers-with-disabilities
- For resources specifically written with MG in mind, go to the MGFA website at

http://myasthenia.org/LivingwithMG/InformationalMaterials.aspx and select Travel Tips Part 1 & Travel Tips Part 2. These two practical documents will help you make your travel plans and provide tips and lists to review and use.

Whether it's a visit to Disney, a sojourn at the shore, or visiting historical sites, a vacation can be just "what the doctor ordered." But for those with health challenges a little more planning may be needed to assure comfort, safety and fun! "Bon voyage!" to all you travelers!

MG Research and Clinical Trials

FDA Accepts sBLA Filing of Soliris® (Eculizumab) as a Potential Treatment for Patients with Refractory Generalized Myasthenia Gravis (gMG)

Alexion Pharmaceuticals, Inc. (NASDAQ: ALXN) announced in a press release on March 8, 2017, that the U.S. Food and Drug Administration (FDA) has accepted for review the Company's supplemental Biologics License Application (sBLA) to extend the indication for Soliris® (eculizumab) as a potential treatment for patients with refractory generalized myasthenia gravis (gMG) who are anti-acetylcholine receptor (AChR) antibody-positive. The sBLA submission is supported by comprehensive data from the Phase 3 REGAIN study. The FDA set a Prescription Drug User Fee Act (PDUFA) date of October 23, 2017. If approved, Soliris would be the first and only complement inhibitor for patients with refractory AChR-positive gMG. Soliris has received Orphan Drug Designation (ODD) for the treatment of patients with MG in the U.S. and EU. Soliris is not approved in any country for the treatment of patients with refractory AChR-positive gMG. Click here to read more

Myasthenia Gravis Trial Shows Encouraging Results

Catalyst Pharmaceuticals has reported that their clinical trial testing Firdapse (amifampridine phosphate) in MG patients with anti-MuSK antibodies (MuSK-MG) met its primary endpoint. The trial was a

randomized, double blind, placebo-controlled, single site, outpatient study assessing Firdapse in patients with MuSK-MG, a rare sub-population of MG patients. MuSK is a receptor tyrosine kinase required for the formation and maintenance of the neuromuscular junction. Click here to read more

Exercise and MG Study Published

The MGFA is pleased to share a journal review article on Exercise and Myasthenia Gravis - a Review of the Literature to Promote Safety, Engagement and Functioning published in the International Journal of Neurorehabilitation by Julia Naumes, Charlene Hafer-Macko and Sarah Foidel. If you are concerned or wondering about exercising with MG, you may find this article helpful. We are pleased to say that the work was supported in part by the MGFA. Click here to read the study

Terumo BCT's Spectra Optia® Apheresis System Is the First and Only Device on the European Market Indicated to Treat Guillain-Barré Syndrome and Myasthenia Gravis using Therapeutic Plasma Exchange

Terumo BCT, a global leader in blood component, therapeutic apheresis and cellular technologies, announced on April 6 that its Spectra Optia® Apheresis System with therapeutic plasma exchange (TPE) has received the CE marked with an indication to treat Guillain-Barré Syndrome (GBS) and myasthenia gravis (MG). The Spectra Optia system is a centrifugal therapeutic apheresis and cell collections platform and is the first and only device on the European market today approved to treat GBS and MG using TPE. GBS and MG are rare and debilitating orphan neuromuscular diseases. GBS has been associated with the Zika virus infection.

The expanded use indications were based on reviews of clinical studies supporting the safety and efficacy of TPE for treating GBS and MG. Various studies showed that by rapidly removing circulating

disease mediators and immune complexes, TPE resulted in increased speed of recovery for the majority of GBS and MG patients when compared to supportive care. A single TPE procedure can rapidly lower all immunoglobulins (Igs).
http://www.terumo.com/about/pressrelease/2017/20170406_01.html

MG Patients in the Media

Sally O'Meara – School of Nursing Educator and MG Patient – Honored by MGFA as "Nurse of the Year" and Featured in Oakland University Newsletter

Sally O'Meara, a special lecturer in the Oakland University School of Nursing and an MG patient, was honored by the MGFA with the organization's 2017 "Nurse of the Year" award. O'Meara received the award at the MGFA National Conference in New Orleans, held March 26-28. O'Meara also was a presenter at the conference on "How to Prepare for Myasthenia Gravis Medical Emergencies." The recognition of Sally's award was featured in the Oakland University newsletter. Sally's connection with MG goes beyond the classroom education she provides Oakland's nursing students. She was diagnosed with MG three years ago after spending the prior four years seeking a definitive diagnosis. Being an R.N. for 26 years and earning a BSN and MSN from Oakland University gives Sally great pride in the university where she has enjoyed teaching the past 11 years. "Despite my challenges, I remain passionate about the nursing profession and I love watching my students turn into wonderful, caring nurses," she said. Click here to read article

MG North Carolina Patient Featured on TV, Promoting Walk

North Carolina's three-year-old MG patient Alexandria Trapp, and her father Ray, were interviewed by WFMY Channel News 2, to promote the North Carolina MG Walk, held April 8 in Greensboro, and also to raise awareness of MG. Click here to watch interview

MG New Orleans Patient Featured on TV, Promoting Walk

2017 New Orleans MG Walk Hero and MGFA Communications Committee Chair Tommy Santora was interviewed on a local TV station, WWL-TV Channel 4, to promote the New Orleans Walk, which raised more than $38,000, and attracted more than 300 attendees. Tommy, 38, has had MG since the age of 12. Click here to watch interview

MG Low Country South Carolina Support Group Leader's Letter to the Editor

Low Country South Carolina MG Support Group Leader, MG patient, and MGFA Communications Committee Member Janet Myder wrote a letter to the editor, "Snowflake Disease" that was published in The Post and Courier newspaper. Janet wrote: "Brian Hicks' Feb. 1 reference to "snowflake" suggests it is a "derisive term that is used to describe anyone who thinks they're too special to have their ideas challenged." That inspires me to note that no two snowflakes are alike — something positive and descriptive that is significant to people who have chronic diseases." She described MG and wrote that it is a "snowflake" disease because individuals are not all affected with the same mixture of symptoms with the same amounts of intensity and they do not all respond to treatment in the same way. She also wrote about the Low Country MG Support Group. Two people who were newly diagnosed with MG learned about the support group meetings only by reading the letter. They attended their first meeting on March 18. Click here to read more

MG and Parkinson's Patient Featured in Fresno Bee

Dwight Harder, 72, has both Parkinson's and MG. His story was featured in The Fresno Bee newspaper. He has had Parkinson's for 15 years and MG for 30 years. "With Parkinson's disease, you have the tendency to want to be an introvert," says 72-year-old Dwight. "When

you can't walk straight, when your voice is soft, when you drool ... Myasthenia gravis — if not taken care of — will kill me," Dwight says. Dwight says he ingests "about 30 pills" throughout the day because without taking medication, his eyelids start to droop. He takes three medications daily for Parkinson's disease, which started as a twitch in his left pinkie finger. At the time, he was working for Carris Reels in Madera. The last five years of employment were tough as his symptoms started to take a physical toll on him, Dwight says. "It got harder and harder to function," he says.
Click here to read more

People Magazine Makes Reference to Roger Smith's MG in 50th Anniversary Article on Smith and wife Ann Margret

77 Sunset Strip Star Roger Smith, who was diagnosed with MG in 1980, and award-winning actress Ann Margret (Bye Bye Birdie) will be celebrating their 50th anniversary in May, and the couple is profiled in the upcoming People magazine.
Click here to read more

Low Country SC MG Support Group Walk Team featured in Moultrie News

The May 3 edition of the Moultrie News featured a photo and story about the Low Country SC MG Support Group MG Walk team. In addition to stating that the Mount Pleasant, SC's support group helped to raise awareness and research funds during the first locally based MG Walk of the Myasthenia Gravis Foundation of America on April 8 in Charleston, the article included information about MG and available treatments and the schedule and location of support group meetings.

Other Health News and Studies

Mayo Clinic Finds Association Between Therapy for Autoimmune Disease and Bone Marrow Disorders

Mayo Clinic researchers have found that Azathioprine, a drug commonly used to treat autoimmune disease, may increase the risk of

myeloid neoplasms. Myeloid neoplasms include a spectrum of potentially life-threatening bone marrow disorders, such as myelodysplastic syndromes and acute myeloid leukemia. The results are published in JAMA Oncology. The results concluded that only azathioprine, associated with an increased risk of therapy-related myeloid neoplasm, was statistically significant. However, other agents used showed a similar trend that was not statistically significant.
Click here to read more

GW Researcher Finds Genetic Cause of New Type of Muscular Dystrophy

A newly discovered mutation in the INPP5K gene, which leads to short stature, muscle weakness, intellectual disability, and cataracts, suggests a new type of congenital muscular dystrophy. The research was published in the American Journal of Human Genetics by researchers from the George Washington University (GW), St. George's University of London, and other institutions.
Click here to read more

Can Virtual Reality Help Us Prevent Falls in the Elderly and Others?

In a study published in Nature Scientific Reports, a research team led by Jason R. Franz, PhD, assistant professor in the Joint UNC/NC State, department of biomedical engineering, used a novel VR system to create the visual illusion of a loss of balance as study participants walked on a treadmill. By perturbing their sense of balance in this way and recording their movements, Franz's team determined how the participants' muscles responded. In principle, a similar setup could be used in clinical settings to diagnose balance impairments, or even to train people to improve their balance while walking. "We were able to identify the muscles that orchestrate balance corrections during walking," Franz said. "We also learned how individual muscles are highly coordinated in preserving walking balance. These things

provide an important roadmap for detecting balance impairments and the risk of future falls." For details click on http://news.unchealthcare.org/news/2017/april/can-virtual-reality-help-us-prevent-falls-in-the-elderly-and-others

Grants for Studying Falls

The Administration on Aging (AoA) within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) announced the possible availability of Fiscal Year (FY) 2017 funds to make three-year grants to 6-8 entities to bring to scale and sustain evidence-based falls prevention programs that will reduce the number of falls, fear of falling, and fall-related injuries in older adults and adults with disabilities. Goal 1: Significantly increase the number of older adults and adults with disabilities at risk of falls who participate in evidence-based programs to reduce falls and fall risks; and Goal 2: Implement innovative funding arrangements to support community-based falls prevention programs beyond the grant period, while embedding the programs into an integrated, sustainable evidence-based prevention program network. For additional information click on https://acl.gov/Funding_Opportunities/Announcements/Index.aspx

Commonwealth Fund Connection

New State Scorecard

The 2017 edition of the Commonwealth Fund Scorecard on State Health System Performance finds that nearly all state health systems improved on a broad array of health indicators between 2013 and 2015. During this period, which coincides with implementation of the Affordable Care Act's major coverage expansions, uninsured rates dropped and more people could access needed care, particularly those in states that expanded their Medicaid programs. Using the most recent data available, the Scorecard ranks states on more than 40 measures of health system performance in five broad areas: health care access, quality, avoidable hospital use and costs, health outcomes, and health care equity. View the scorecard's findings

through the Commonwealth Fund interactive digital report and click on data center to compare the performance of individual states.

Essential Facts About Health Reform Alternatives: High-Risk Pools

The Commonwealth Fund examined the effect that high-risk pools, created under the Affordable Care Act (ACA), have had on people with pre-existing conditions. The Fund projected the effect that would result through proposed alternatives to the ACA currently being considered in Congress. For example, some Americans now covered by an ACA marketplace plan may ultimately have more expensive coverage providing less financial protection. The experience with state-based high-risk pools and the more recent national Pre-existing Conditions Insurance Plan (PCIP) program indicates that many current marketplace enrollees would face very high premiums and deductibles. Learn more here.

AARP

No Wrong Door: Person-and Family-Centered Practices in Long Term Service and Supports

On March 22 the AARP Public Policy Institute released No Wrong Door: Person- and Family-Centered Practices in Long-Term Services and Supports and Checklist to report on states' transformation of their LTSS access functions into "Person-Centered No Wrong Door Systems." These systems include an array of organizations, such as, Area Agencies on Aging, Centers for Independent Living, and state agencies such as Medicaid agencies and state units on aging. Older adults, people with disabilities, and their families can access services through these agencies in a variety of ways. The report provides concrete examples of how seven No Wrong Door Systems are promoting person- and family-centered practice. The LTSS Scorecard--written by the AARP Public Policy Institute and funded by The SCAN Foundation and The Commonwealth Fund--measures state-level performance of LTSS systems that assist older people, adults with disabilities, and their family caregivers. The five scores reported are affordability and access to care, choice of location and provider, quality of life and care, support of family caregivers, and effective transitions.

News from the Public Sector

U.S. House of Representatives www.congress.gov
On March 8, the House Committee on Education and the Workforce approved H.R. 1313 – Preserving Employee Wellness Programs Act, which would allow employers to require employees to undergo genetic testing and share such information under a workplace wellness program. The Committee claimed that it would allow employers to offer employee wellness plans, help them promote a healthy workforce and would lower health care costs. Employees who refuse to be tested could be subject to higher insurance premiums. The committees on Energy and Commerce, and Ways and Means are considering the bill, and it is expected to be included in the larger healthcare replacement of the Affordable Care Act ("ACA").
Currently, employers are prohibited and restricted from asking to collect genetic information from employees under the Genetic Information Nondiscrimination Act ("GINA"), the Americans with Disabilities Act ("ADA") and other state laws. The bill specifically states that GINA and other protections will not apply to genetic testing conducted under a workplace wellness program or a program relating to health promotion or disease prevention.

National Organization for Rare Disorders (NORD) announced its strong opposition H.R.1313. In a written statement, NORD said that the proposal would roll back decades of critical patient protections and allow unscrupulous employers to punish individuals for their genetic makeup through insurance or workplace discrimination. The privacy of millions of individuals with rare diseases could be violated by making incredibly personal and private genetic information legally accessible to employers under the threat of harsh financial punishment. Family members would also be at risk of forcibly discovering information on genetic predispositions they did not electively pursue. NORD leaders promised they will do everything in their power to prevent the bill from moving forward in its current form. They stated that they would work with the over 260 member organizations, including MGFA, and thousands of intrepid patient advocates that NORD represents to ensure this bill does not become law.

Health and Human Services (HHS) HHS.gov
On March 20 HHS announced creation of a new web page designed to highlight "the regulatory and administrative actions the Department is taking to relieve the burden of the current healthcare law and support a patient-centered healthcare system." According to HHS, the actions are part of a broader plan to repeal and replace the Affordable Care Act. Describing the plan, HHS Secretary Tom Price said, "We're taking action to improve choices for patients, stabilize the individual and small-group insurance markets, and expand access to more affordable coverage. This page will be the place to go for updates on our ongoing efforts."
Click here to see the newly launched webpage explaining the Department's actions.

U.S. Food and Drug Administration (FDA) www.fda.gov
Health Disparities
The FDA reports that scientific researchers, funded by the FDA, are working in collaboration with the FDA to determine how to reduce Health disparities, differences in the health status of different groups of people, among racial and ethnic minorities. These differences may be the frequency of disease occurrence, the severity of disease or how often a disease results in death among certain groups. Health disparities exist for many conditions, including HIV/AIDS, hepatitis, diabetes, cancer, and heart disease. Racial and ethnic minorities may be more likely to have these diseases or may be more likely to have serious effects from them. "Some of these differences may be partly due to the circumstances in which people are born, grow up, live, work and age, as well as by their differences in access to healthcare," says Jonca Bull, M.D., the FDA's assistant commissioner for minority health. "But we also need to explore whether there is a biological basis for these differences, including how safe and effective a medical product might be in the individual. It's another way to focus the lens on personalized medicine."
The FDA link to more information is: Get the scoop on what the FDA is doing. Additional information is also available at HHS: Disparities -- Healthy People 2020 and the National Institutes of Health: Health Disparities.

FDA Consumer Health Information

Would Your Child Benefit from a Clinical Trial? Please click on this link for details. According to the FDA, only about 50% of drugs approved by FDA have been labeled for use in children to date. So, by necessity, doctors routinely treat children with a drug that has been tested in adults and approved for adult use, but may be untested in children or tested in a different group of children. FDA further states that children's responses to drugs can't always be predicted from data collected in studies of adults. A child grows, and the metabolism changes as he or she gets older. "These changes mean the child may have a different susceptibility to side effects over time, even if the dose remains the same. Or we may need to use a different dose to have the same treatment effect. We may think we can predict some of these differences, but we really can't without studying them," says Robert (Skip) Nelson, M.D., Ph.D., Deputy Director and Senior Ethicist of the Office of Pediatric Therapeutics at the FDA.

More Transparency Needed at the FDA

The Johns Hopkins Bloomberg School of Public Health announced that a group of leading researchers has created a Blueprint for Transparency at the FDA to advance the development of safe and effective new products. The researchers include senior faculty from the Johns Hopkins Bloomberg School of Public Health, Harvard Medical School/Brigham and Women's Hospital, Yale Medical School, and Yale Law School. The project was organized by Joshua Sharfstein, MD, a former FDA Principal Deputy Commissioner and Professor of the Practice at the Bloomberg School. "FDA is more than an agency that makes regulatory decisions," says Sharfstein, "It is also a repository for scientific analysis and data that, if more widely available, would improve understanding of existing therapies, the pharmaceutical pipeline and opportunities for innovative product development." Sharfstein and Michael Stebbins, PhD, of the Laura and John Arnold Foundation authored an overview of the Blueprint in JAMA that was released online March 13. The full report, released simultaneously

online at www.jhsph.edu/blueprintFDA, makes 18 recommendations in five principal areas.

Centers for Disease Control and Prevention (CDC) www.cdc.gov

Preventing Tick Bites

As the summer months are approaching and we spend time outdoors, precautions are needed to avoid tick bites. The CDC provides extensive information about ticks including how to avoid them, repelling ticks from our bodies and clothing, finding and removing ticks from our bodies, symptoms of tickborne illnesses, and protecting pets from encountering ticks. Go to https://www.cdc.gov/ticks/index.html for details. For additional information provided by the University of Manitoba, including a video about how to check for ticks, click on http://news.umanitoba.ca/tips-on-staying-safe-during-tick-season/

The Government Accountability Office (GAO) www.gao.gov

On March 15, the Government Accountability Office (GAO) released Health Information Technology: HHS Should Assess the Effectiveness of Its Efforts to Enhance Patient Access to and Use of Electronic Health Information. GAO-17-305. The GAO stated that health care providers that participated in HHS's Medicare Electronic Health Record Incentive Program offered nearly 9 out of 10 patients the ability to access their health information online. The GAO found that relatively few of these patients accessed their records online, and typically did so in response to a medical visit. GAO also found that HHS doesn't know how effective its efforts to increase online access have been. GAO recommended that HHS develop performance measures to assess the effectiveness of these efforts. For the full report, click on http://www.gao.gov/products/GAO-17-305 and for highlights click on http://www.gao.gov/assets/690/683387.pdf

On March 15 the GAO also released testimony presented to the U.S. Senate Committee on Veterans Affairs, Veterans' Health Care: Limited Progress Made to Address Concerns That Led to High-Risk Designation. GAO-17-473T. The GAO stated that the Department of Veterans Affairs (VA) has acted to partially meet two of the five criteria GAO uses to assess removal from the High-Risk List (leadership commitment and an action plan), but it has not met the other three (agency capacity, monitoring efforts, and demonstrated progress). The VA provided GAO with an action plan in August 2016 that acknowledged the deep-rooted nature of the five areas of concern GAO identified. Although VA's action plan outlined some steps that it plans to take over the next several years, several sections were missing analyses of the root causes of the issues, resources needed, and clear metrics to measure progress. To view the testimony, click on http://www.gao.gov/products/GAO-17-473T. For highlights, click on http://www.gao.gov/assets/690/683382.pdf

On March 2, the GAO released its report, Antibiotics: FDA Has Encouraged Development, but Needs to Clarify the Role of Draft Guidance and Develop Qualified Infectious Disease Product Guidance. GAO-17-189, January 31. The GAO reported that the Food and Drug Administration (FDA) released updated or new guidance for antibiotic development, and used the qualified infectious disease products (QIDP) designation to encourage the development of new antibiotics. As of August 2016, FDA had coordinated the release of 14 updated or new guidance documents on antibiotic development, in compliance with Generating Antibiotic Incentives Now (GAIN) provisions of the Food and Drug Administration Safety and Innovation Act of 2012. However, the GAO found that half of these guidance documents remain in draft form. To read the full report, click on http://www.gao.gov/products/GAO-17-189. For highlights, click on http://www.gao.gov/assets/690/682392.pdf

National Organization for Rare Disorders (NORD)
Spring 2017 State Policy Legislative Tracker
NORD released its Rare Acton Network's Spring 2017 State Policy Legislative Tracker that shows on a state-by-state basis the legislation that NORD is tracking. NORD is taking action in 42 states and the District of Columbia. To view the tracker, click on Download the document (click)

Honorees Announced for 2017 Rare Impact Awards
NORD announced the people, organizations, and innovators who will be honored at its 2017 Rare Impact Awards on May 18 in Washington, D.C. The 2017 honorees include patients Ellie McGinn, Christine Grube, and Brandon Hudgins; caregiver and White House Precision Medicine Initiative appointee Matthew Might, Ph.D.; patient and advocate Beth Nguyen, R.N.; researchers and clinicians Robert Desnick, Ph.D., M.D., Frederick Kaplan, M.D., and Cynthia Tifft, M.D.; national health leaders Rep. Diana DeGette (D-CO) and Sen. Johnny Isakson (R-GA); A Twist of Fate – ATS, a nonprofit patient organization serving the Arterial Tortuosity Syndrome community; and industry innovators Advanced Accelerator Applications USA, Biogen, CSL Behring, Intercept Pharmaceuticals, Jazz Pharmaceuticals, and Sarepta Therapeutics.

American Autoimmune Related Diseases Association (AARDA)
On March 28, the AARDA released the findings of its online survey of 1,287 autoimmune disease (AD) patients. The findings may be accessed by clicking on http://www.newswise.com/institutions/newsroom/3263/ AARDA found that the vast majority of autoimmune disease patients do not believe that U.S. elected officials, including President Trump as well as other Federal and State elected officials, understand that autoimmunity is a major U.S. health issue. In addition, they voice apprehension over the future of health insurance and what it means for their care, and

believe that legislation must be in place to prevent insurance companies from taking medical decisions away from patients' doctors.

AARDA announced major findings including: Ninety four percent of AD patients surveyed agree that "Federal autoimmune disease research is significantly underfunded ($821M) when compared to cancer ($5.4B) and heart disease ($1.7B). Increasing federal funding for autoimmune research should be a top national health care priority for the President and members of Congress." A large majority are concerned that the following areas of healthcare policy will be an issue in the future and nearly all believe these issues should be considered as the ACA is repealed and replaced, including: - Pre-Existing Conditions (75 percent and 91 percent respectively) - High Cost/Co-Pays for Medicine (78 percent and 93 percent respectively) - High Insurance Premiums/Deductibles (76 percent and 92 percent respectively) - Access to Specialists (64 percent and 89 percent respectively) - Narrow Provider Networks (60 percent and 85 percent respectively)