

# THIS WEEK IN CAREGIVING



March 16, 2021

## INTRODUCING A *Unified Strategy to Support Family Caregivers Across the Nation*



NOW AVAILABLE!

**FROM MOMENTUM TO MOVEMENT:**  
DEVELOPING A UNIFIED STRATEGY  
TO SUPPORT FAMILY CAREGIVERS  
ACROSS THE NATION

DOWNLOAD NOW

The National Alliance for Caregiving (NAC) has released *From Momentum to Movement: Developing a Unified Strategy to Support Family Caregivers Across the Nation*.

This report represents the first iteration of a living document and compilation of resources to help guide advocates in developing statewide caregiving strategies that address community-level needs. This report presents a strategic process to foster the development of actionable goals in new state plans. It also includes core policy recommendations in person-centered domains intended to coordinate alignment across key global, national, and state-level priorities and to strengthen movement toward a robust, unified caregiving strategy for caregivers across the lifespan.

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## CAREGIVING IN THE NEWS

**Opinion: 50 Million Americans Are Unpaid Caregivers.  
We Need Help.**

This opinion piece was written by Kate Washington, a caregiver for her husband for

six years through his treatment for lymphoma. She is the author of an upcoming book on caregiving.

"The plight of family caregivers, who often compromise work, finances, friendships and their own health to support their ill or disabled loved ones, has long been overlooked in U.S. policy. While some states offer programs to help caregivers, they can be inadequate and hard to navigate. The coronavirus pandemic has revealed many problems in our health system, and few more starkly than the way it both undervalues and relies on caregivers.

I became painfully familiar with caregiving's challenges during Brad's months of chemo in 2015, but it was his 2016 stem-cell transplant — a last-ditch treatment for relapsed cancer — that showed me just how broken our system is. When he was discharged, he was immunocompromised, blind, too weak to walk unassisted, and unable to eat more than half his calories."

*From: The New York Times | February 22, 2021*

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## A Love Letter to Male Caregivers

"We need to just make it normal, make it just a fact of life and make it not something to be ashamed of. It should just be a conversation and an expectation that it's going to be part of life and that's okay and there's nothing wrong with that. The key word is normalization and setting the expectation that that is going to happen most likely in one way or another and that we shouldn't be surprised and we should be very ready when that moment does come."

*From: The Hill | February 14, 2021*

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## Respite Program Offers Free Help to Military Caregivers

"For the caregivers who do secure respite relief assistance, the benefits are numerous. To this end, AARP and the Elizabeth Dole Foundation announced that Respite Relief for Military and Veteran Caregivers, originally a pilot program in a handful of states, is going nationwide. The program gives some eligible family caregivers access to no-cost, short-term assistance to help those caring for wounded, ill or injured veterans or service members. It helped 500 families in 2020."

*From: AARP | February 18, 2021*

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## EVENTS & OPPORTUNITIES

### INTERVIEW OPPORTUNITY FOR CAREGIVERS

#### Interview Opportunity with Clara Health

Our partner, [Clara Health](#), is looking to interview a few caregivers from diverse backgrounds! To learn more about this paid opportunity and to apply, please click [here](#) or the red link below.

If you have any questions, please contact Clara's Patient Advocacy & Community Engagement Lead, David Banda, at [david@clarahealth.com](mailto:david@clarahealth.com).

APPLY  
>

## UPCOMING EVENTS



### Fast-Forward: A Documentary That Helps You Change Your Life

Premiers March 24, 2021 | PBS

Fast-Forward follows four millennials and their parents as they travel through time to meet their future selves. Wearing an MIT-produced “aging empathy suit” and working with professional make-up artists, they grapple with the realizations, conversations and mindset required to age successfully. Ultimately, the families learn they have more control over how they age than they thought.

Next Avenue has partnered with the film to produce courses and a digital toolkit of resources, including step-by-step instructions and a master checklist, designed to help viewers prepare their own aging plans.

Click the link below to learn more about how you can watch on March 24th.

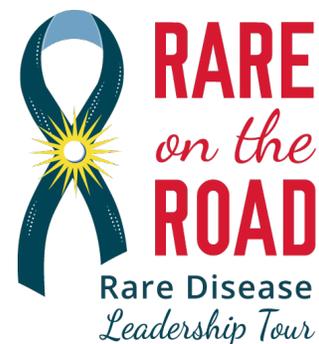
REGISTER  
>

### RARE on the Road: Global Genes Rare Disease Leadership Tour

March-May 2021

Since 2017, Global Genes and the EveryLife Foundation have partnered to host RARE on the Road events around the country, developing the next generation of advocacy leaders. With feedback from the community, RARE on the Road 2021 will consist of one interactive webinar, open to all who wish

to attend, regardless of their geographic location, and three virtual, state-specific meetings focusing on issues and resources relevant to residents in Nevada, Florida, and Illinois. Click the red link below to learn more.



A Rare Disease Leadership Interactive Webinar will be hosted on March 23, 2021 from 11 AM - 1:30 PM EST. [Click HERE to register now.](#)

LEARN MORE



## Health Equity Summit

**April 28, 2021 | 11 AM - 2:30 PM EST | Online**

Amgen's 2020 Health Equity Summit illuminated the value of cross-sector/functional partnerships intended to disrupt systemic barriers to good health among vulnerable populations.

Amgen's 2021 Health Equity Summit



The 2021 Summit will highlight innovative collaborations that have emerged from this time of adversity and best practices for building strategic partnerships to help make American health care more equitable for all people.

REGISTER



## CALL FOR APPLICATIONS

### Apply to Be a Health and Aging Policy Fellow

**Deadline: April 15, 2021**



## HEALTH AND AGING POLICY FELLOWS

Candidates with a strong commitment to health and aging issues, leadership potential, and interest in aging-relevant policy work are invited to join the next class of Health and Aging Policy Fellows (2021-2022).

The Health and Aging Policy Fellows Program continues to make great strides in advancing policy with creative solutions in the context of COVID-19.

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## CALL FOR PUBLIC COMMENTS

### Help the NIH End Structural Racism in Biomedical Research

**Deadline: April 9, 2021**

The [NIH](#) is requesting a moment of your time to respond to a [Request for Information](#) for input on practical and effective approaches to improve and strengthen racial equity, diversity, and inclusion across all facets of the biomedical research enterprise, both within NIH and the external community, and expand research to eliminate or lessen health disparities and inequities.

The NIH invites you to share your perspective and recommendations as we thoughtfully consider NIH's proactive approach to address racial and health inequities in biomedical research.

Comments can be submitted through the [submission website](#) and must be received by April 9, 2021.

[SUBMIT COMMENTS](#)



## CAREGIVER AND PATIENT STUDIES

### COVID-19 Patient Clinical Trial

We're reaching out to our patient and caregiver community to raise awareness of an ongoing clinical trial for the prevention of long-term lung damage in hospitalized COVID-19 patients. If you or a care recipient required ventilation due to these respiratory complications, you could trial a potential investigational treatment for the prevention of long-term lung damage, as well as advance understanding of the long-term effects of the virus.

Begin exploring with [Leapcure](#) by pre-screening [HERE](#).

[LEARN MORE](#)



## RESEARCH & RESOURCES

### NEW RESEARCH

#### UPitt Briefing Report: Households with Multiple Persons with Disability in Pennsylvania



"Examining disability in households with multiple persons with disability raises important new questions about the role of formal and informal support for these households. Our report summarizes the prevalence of these households, but more fine-grained assessments will be required to better understand the unique needs of this

understudied population."

*From: University of Pittsburgh | "Briefing Report: Households with Multiple Persons with Disability in Pennsylvania"*

[SEE MORE](#)



### The National Economic Burden of Rare Disease Study

This study, conducted by the Lewin Group on behalf of the EveryLife Foundation for Rare Diseases, is the first of its kind, providing the most comprehensive assessment of the total economic burden of 379 rare diseases in a single year. This study identified direct medical costs, via an analysis of claims data, and indirect costs associated with productivity loss and non-medical and other uncovered healthcare costs, via a survey of 1,399 members of the rare disease community.

A February 25<sup>th</sup> press release from the EveryLife Foundation announced the study and acknowledged the tremendous collaborative effort, most notably from the rare community ourselves, required to bring the study to life. Topline findings were presented at the Rare Disease Congressional Caucus Briefing on the same day in a presentation titled, "Economic Burden of Rare Diseases in America: A Public Health Crisis."

The study found that the total economic burden of 379 rare diseases was nearly \$1 trillion in the United States in 2019, exceeding estimates for many of the country's most prevalent chronic diseases.

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## RESOURCES

### One Year Since the WHO Declared the COVID-19 Pandemic

Last week marked the one year anniversary since the **World Health Organization** (WHO) declared the COVID-19 pandemic. It's been a year since COVID-19 forced us to adapt to a new life. The pandemic has taken a toll on many of us. Most of us have experienced some kind of loss because of #COVID19. We may feel different emotions—stress, grief, or anxiety. #HowRightNow can help us deal with some of these feelings. Click the link below to learn how you or someone you know can cope.

How  
Right  
Now

**Reach out.  
Connect to friends,  
family or neighbors.**

[→ HowRightNow.org/Talk](https://HowRightNow.org/Talk)

**SEE MORE**



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