National Study on Caregiving for People Living with Inflammatory Bowel Disease (IBD) Unveils Unique Challenges

*Research demonstrates the need for greater support for the IBD caregiving community in a report from the National Alliance for Caregiving in partnership with the Crohn's and Colitis Foundation and ImproveCareNow*

WASHINGTON (PRWEB) September 25, 2019 -- With more than 3.1 million Americans living with Crohn’s disease or ulcerative colitis, there is little understanding about the impact of the disease on family caregivers. Today, results from a national survey of more than 700 caregivers of inflammatory bowel disease (IBD) patients were released revealing the burden of disease on family and friends, and the need for greater support for the inflammatory bowel disease (IBD) caregiving community.

The National Alliance for Caregiving (NAC), the Crohn’s & Colitis Foundation, ImproveCareNow, and researchers from Crimson Research at New Mexico State University (NMSU) worked collaboratively to develop the study, which offers new insights on how caregiving for chronic digestive diseases might differ from caregiving for progressive diseases such as dementia or age-related illness. The study was funded through a grant from the David R. Clare and Margaret C. Clare Foundation.

“Caregiving is not just an aging issue and that's a message that came across loud and clear in this report,” said C. Grace Whiting, J.D., President and CEO of the National Alliance for Caregiving. “Our research shows that IBD caregivers as multi-tasking superheroes. And it uncovered gaps that must be addressed, such as engaging medical professionals to provide training to friends and family members who provide care.”

Specifically, the survey results showed:
- On average, the respondents had been providing care for nearly eight years and providing approximately 20 hours of care each week.
- 81% of respondents worked full- or part-time while providing care and many of these individuals reported that providing care caused them to lose time at work (94%) and their productivity to suffer (55%).
- Eight in 10 caregivers reported providing assistance by talking/communicating with healthcare professionals, providing transportation, and grocery shopping.
- 92% reported providing or preparing meals including specialty foods, which was cited as one of the most difficult tasks
- Six in 10 caregivers reported assisting with medication, doing housework, and managing finances.
- Many caregivers assisted with activities of daily living, including toileting (30%), bathing (28%), or dealing with incontinence (28%)

“Caregivers are key members of the care team, providing physical, emotional, and financial support to people living with IBD,” said Laura Wingate, Senior Vice President, Education, Support, & Advocacy for the Crohn’s & Colitis Foundation. “While focusing on their loved one, the caregiver’s own needs are often overlooked. Many experience stress, anxiety, guilt, and a variety of other emotions while providing care. They often don’t have time to decompress or take care of themselves. We need to do more to ensure that caregivers have the resources and time for respite care to ensure they can best advocate for their loved ones.”

The survey showed the profound impact that caregiving can have on one’s physical and mental health. Specifically, the survey found:
- Emotional stress was common among caregivers with 59% experiencing emotional stress, 49% feeling
overwhelmed, and 16% reporting experiencing depression from providing care.
- 35% felt guilty because they thought they should be doing a better job of providing care.
- More than 6 in 10 reported struggling with a sense of loss over what the care recipient’s life would have been like without IBD.
- Physical health also is affected, with 44% reporting feeling fatigued and 39% reporting not getting enough sleep
- IBD caregivers are exceptionally persistent in their care -- 28% sought access to clinical trials, yet trials were rated the most difficult to access.
The full results of the survey can be viewed online at www.caregiving.org/ibd.

About Crohn’s Disease & Ulcerative Colitis
Known collectively as inflammatory bowel diseases (IBD), Crohn’s disease and ulcerative colitis affects nearly 1 in 100 people. They are painful, medically incurable diseases that attack the digestive system. Crohn's disease may attack anywhere along the digestive tract, while ulcerative colitis inflames only the large intestine (colon). Symptoms may include abdominal pain, persistent diarrhea, fever, and weight loss. Many patients require numerous hospitalizations and surgery. Most people develop the diseases between the ages of 15 and 35; however, the incidence is increasing in children.

About the National Alliance for Caregiving
Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at http://www.caregiving.org.

About Crohn’s and Colitis Foundation
The Crohn’s & Colitis Foundation is the largest non-profit, voluntary, health organization dedicated to finding cures for inflammatory bowel diseases (IBD). The Foundation’s mission is to cure Crohn’s disease and ulcerative colitis, and to improve the quality of life of children and adults who are affected by these diseases. The Foundation works to fulfill its mission by funding research; providing educational resources for patients and their families, medical professionals, and the public; and furnishing supportive services for those afflicted with IBD. For more information visit http://www.crohnscolitisfoundation.org, call 888-694-8872, or email info@crohnscolitisfoundation.org.

About ImproveCareNow
ImproveCareNow (ICN) is a Learning Health Network dedicated to transforming care, health and costs for all children and youth with Crohn’s disease and ulcerative colitis by building a sustainable collaborative chronic care network. ICN enables parents, families, clinicians and researchers to work together in a learning health care system to accelerate innovation, discovery and the application of new knowledge. For more information visit http://www.improvecarenow.org or email info@improvecarenow.org.

About Crimson Research
Crimson Research, College of Health and Social Services at New Mexico State University specializes in program evaluation, survey construction and analysis, comprehensive program implementation, and basic and applied research across disciplines. The organization has a record of high-quality research and dissemination as
well as a history of successful collaboration with government and community agencies and intervention teams. Externally-funded and located within New Mexico State University, Crimson Research guides organization directors, policy-makers, and researchers through the design and implementation process. Learn more at www.health.nmsu.edu/crimson-research.
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