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November 25, 2020

The Aplastic Anemia and MDS International Foundation (AAMDSIF) and Acceleron Pharma Inc. Announce Partnership Exploring the Mental Health Implications of Myelodysplastic Syndromes (MDS) Among Adult MDS Patients and Their Caregivers in the U.S.

(Bethesda, MD, November 25, 2020) The Aplastic Anemia and MDS International Foundation (AAMDSIF) and Acceleron Pharma Inc. are partnering in an effort to better understand the mental health implications of myelodysplastic syndromes (MDS) among adult MDS patients and their caregivers in the U.S. An online survey will be implemented to identify the mental health needs of MDS patients, and the results will be used to develop actionable solutions to address these concerns. A public report on the findings will also be released in 2021.

Myelodysplastic syndromes (MDS) represent a heterogeneous group of hematopoietic disorders, derived from an abnormal multipotent progenitor or stem cell and characterized by bone marrow failure, manifest as peripheral blood cytopenias involving one or more lineages. By definition, MDS are clonal disorders in which hematopoiesis is dominated by one or a small number of hematopoietic clones and are associated with a risk of clonal evolution, including progression to acute myeloid leukemia (AML). Patients diagnosed with lower-risk MDS may be treated with active surveillance or with supportive care, while those diagnosed with higher-risk MDS receive more active treatment.

The vast majority of MDS research has focused on pathophysiology and therapeutic targets, with limited attention paid to the impact of the disease and treatment on patients’ quality of life. Symptoms and side effects such as fatigue and short-term memory loss can make daily life difficult, while concerns over financial burden and support resources can increase the psychosocial toll of MDS on both patients and caregivers. These chronic sources of anxiety and frustration may influence patient outcomes without some type of intervention.

“Our priority at AAMDSIF is to support patients and caregivers throughout their MDS journey, and there is a significant need to address the impact of MDS on their mental health as they deal with the shock, uncertainty, and
fear of the unknown that may accompany a diagnosis of MDS,” said Neil Horikoshi, CEO and Executive Director of AAMDSIF. “We believe this study will help us to develop recommendations and resources for caregivers and health care providers that focus on the emotional well-being of MDS patients.”

“We’re pleased to be involved in this partnership with AAMDSIF,” said Habib Dable, President and Chief Executive Officer of Acceleron. “Patient well-being is our utmost priority, and that includes the physical and emotional health not only of the patients themselves but also of those in the support networks upon which they rely. We’re looking forward to the valuable insights that should emerge from this important initiative.”

About Aplastic Anemia and MDS International Foundation
AAMDSIF is the world’s leading nonprofit health organization dedicated to supporting patients and families living with aplastic anemia, myelodysplastic syndromes (MDS), paroxysmal nocturnal hemoglobinuria (PNH), and related bone marrow failure diseases. The Foundation provides answers, support, and hope to thousands of patients around the world.
For more information please visit www.aamds.org. Follow AAMDSIF on social media: @aamdsif on Twitter; @aamds on Facebook

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About Acceleron
Acceleron is a biopharmaceutical company dedicated to the discovery, development, and commercialization of therapeutics to treat serious and rare diseases. Acceleron’s leadership in the understanding of TGF-beta superfamily biology and protein engineering generates innovative compounds that engage the body’s ability to regulate cellular growth and repair.

Acceleron focuses its commercialization, research, and development efforts in hematologic and pulmonary diseases. In hematology, REBLOZYL ® (luspatercept-aamt) is the first and only erythroid maturation agent approved in the United States, Europe, and Canada for the treatment of anemia in certain blood disorders. REBLOZYL is part of a global collaboration partnership with Bristol Myers Squibb. The Companies co-promote REBLOZYL in North America and are also developing luspatercept for the treatment of anemia in patient populations of MDS, beta-thalassemia, and myelofibrosis.

For more information, please visit acceleronpharma.com. Follow Acceleron on social media: @AcceleronPharma and LinkedIn.