

**Bone Marrow Failure Disease Scientific Symposium - Physicians**

with interests in immunosuppressive therapy, stem cell transplantation and basic scientists in cell biology, immunology education are expected to attend this October meeting. Distinguished researchers from around the world will present at this symposium, the purpose of which to provide an optimum opportunity to exchange ideas relating to the etiology, genetics, pathophysiology, epidemiology, and treatment of bone marrow failure diseases. A report for patients will be made available after the meeting. Register at [www.aamds.org](http://www.aamds.org) or contact [baker@aamds.org](mailto:baker@aamds.org).

**Dr. Jaroslaw P. Maciejewski**, The Cleveland Clinic, and **Dr. Neal S. Young**, National Heart, Lung, and Blood Institute are co-chairing the event.

*Scientific speakers include:* **Dr. Andre Bacigalupo**, Ospedale San Martino, Italy; **Dr. Theo de Witte**, University Hospital Nijmegen, The Netherlands; **Dr. Elihu Estey**, University of Texas MD Anderson Cancer Center, Texas; **Dr. Rupert Handgretinger**, St. Jude Children's Research Hospital, Tennessee; **Dr. Peter Hillmen**, Pinderfields Hospital, United Kingdom; **Dr. Surapol Issaragrisil**, Siriraj Hospital, Mahidol University, Thailand; **Dr. Alan List**, H. Lee Moffitt Cancer Center & Research Institute, Florida; **Dr. Lucio Luzzatto**, Istituto Nazionale per la Ricerca sul Cancro Largo, Italy; **Dr. Jaroslaw Maciejewski**, The Cleveland Clinic, Ohio; **Dr. David Margolis**, Children's Hospital of Wisconsin, Wisconsin; **Dr. Judith Marsh**, St. Georges Hospital Medical School, United Kingdom; **Dr. Jeffrey Mollidrem**, University of Texas MD Anderson Cancer Center, Texas; **Dr. Shinji Nakao**, Kanazawa University, Japan; **Dr. Elaine Sloand**, National Heart, Lung, and Blood Institute, Maryland; **Dr. Gerard Socie**, Universite Paris VII & Hopital Saint Louis, France; **Dr. Andre Tichelli**, University Clinics, Switzerland; and **Dr. Neal Young**, National Heart, Lung, and Blood Institute, Maryland.

**Connect With Others Taking Iron Chelation Therapy**

If you are receiving iron chelation therapy please contact Elizabeth Bradley at 800.747.2820 or [bradley@aamds.org](mailto:bradley@aamds.org) to connect with other patients and share your experiences or offer support. As a current member of the Global Volunteer Network receiving chelation therapy, please contact Elizabeth to update your information. Thank you for offering your time to help us help others!

**Joining Our Patient Registry Helps Researchers Learn More About These Rare Diseases**

AA&MDSIF maintains a Patient Registry, since AA, MDS, and PNH are not reportable diseases; therefore, statistics are not presently available to assist researchers and medical studies. Please complete the Patient Registry Questionnaire online for future statistical analysis in order to allow researchers to work towards a cure for these diseases. Contact Julie Bast at [bast@aamds.org](mailto:bast@aamds.org) or 800.747.2820 for more information or to request a copy of the questionnaire by postal mail.

**Visit Patient Clinical Trials for descriptions of newly-listed clinical studies:**

- Cleveland Clinic Foundation – A Phase II Trial of Combination Therapy with Thalidomide, Arsenic Trioxide, Dexamethasone, and Ascorbic Acid (TADA) in Patients with Chronic Idiopathic Myelofibrosis or Overlap Myelodysplastic/Myeloproliferative Disorders. Mikkael Sekeres, M.D. (Principal Investigator)
- Cleveland Clinic Foundation – A Study of Darbepoetin Alfa in Anemic Subjects with Low Risk Myelodysplastic Syndrome. Mikkael Sekeres, M.D. (Principal Investigator)
- Pennsylvania State University, General Clinical Research Center – Quality of Life in Patients with Paroxysmal Nocturnal Hemoglobinuria. Sara Higgins (Principal Investigator)
- Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins – Phase I Study of MS-275 and Azacitidine in Patients With Myelodysplastic Syndromes, Chronic Myelomonocytic Leukemia, or Acute Myeloid Leukemia. Steven Gore, MD (Principal Investigator)
- Novartis Oncology - Trials with Exjade (ICL-670) are anticipated to begin in early April. Please contact the Novartis Oncology Clinical Trials line at 800-340-6843 in early April for more information.

**The following clinical studies are now closed:**

- Memorial Sloan-Kettering Cancer Center – Phase I clinical trial of oral suberoylanilide hydroxamic acid-SAHA (MSK 390) in patients with advanced solid tumors and hematologic malignancies. Mark Heaney, MD, PhD (Principal Investigator)
- Memorial Sloan-Kettering Cancer Center – Tolerability and PK/PD of multiple oral doses of CT53518 in patients with acute myelogenous leukemia. Mark Heaney, MD, PhD (Principal Investigator)
- Novartis Pharmaceuticals (Dana Farber Cancer Institute, Boston) – Phase I, open-label, dose escalating study to evaluate the safety, biologic activity and pharmacokinetic profile of LAQ824 in patients with relapsed or refractory AML, CLL, or CML in blast crisis, or advanced MDS.
- Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins – Phase I dose de-escalation to minimal effective pharmacologic dose trials of sodium phenylbutrate in combination with 5-Azacitidine in patients with MDS. Steven Gore, MD (Principal Investigator)
- University of Washington – Interleukin-2 in treating patients with MDS. John Thompson, MD (Principal Investigator)

**For current information on clinical research studies**, risks, benefits, and what to expect while participating in a study contact Elizabeth Bradley, Clinical Trials Educator, [bradley@aamds.org](mailto:bradley@aamds.org) or 800.747.2820.

This e-bulletin is published by  
**Aplastic Anemia & MDS International Foundation, Inc.**  
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